

**PERSONAL ASSISTANTS AND COLLABORATIVE DECISION MAKING:  
PROMOTING A BETTER BALANCE OF AUTONOMY AND WELL-BEING FOR  
ADULTS WITH MODERATE, MILD, AND BORDERLINE MENTAL RETARDATION**

by

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Autonomy is a core value of American tradition and is promoted in health care through the doctrine of informed consent. The notion underlying informed consent is that patients should have the right to decide, and are often in the best position to know, what will enhance their own well-being. Although this ethic has been extended to incompetent patients, by employing surrogate decision making, providing surrogate decision makers for adults with moderate, mild, and borderline mental retardation (“M-BMR”), who could potentially make their own decisions if adequate supports were offered, unreasonably restricts the autonomy of such individuals and often results in disregard for the patients’ human dignity.

This thesis recommends that health care institutions provide a personal assistant for all health care visits involving adults with M-BMR. In her role as an advocate for the patient, the personal assistant would offer a less restrictive means of promoting the patient’s autonomy in medical decision making than has limited guardianship, thus furthering the goals of guardianship reform that limited guardianship has been unable to do. Serving as an educator and translator, the personal assistant would provide a means to equalize the patient’s opportunity to understand the diagnosis, treatment options, and risks and benefits of those treatments. Alternatively, in

cases where a surrogate decision maker is required, the personal assistant would aid in equalizing the patient's opportunity to understand what is happening during medical procedures by ensuring continued communication with the patient with M-BMR. Finally, having training in ethics, the personal assistant would foster a collaborative approach to medical decision making that recognizes the importance of incorporating both the physician's experience and knowledge and the family member or caregiver's unique understanding of the patient in the medical decision. Together, the personal assistant and the collaborative decision making approach will enhance discussion between the physician, patient, and family member or caregiver, thereby helping balance the autonomy and the well-being of the patient with M-BMR, while also ensuring that the patient's dignity is respected.

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## CHAPTER 1: INTRODUCTION

### 1.1 WHAT IF IT WERE YOU?

Picture yourself in an unfamiliar doctor's office surrounded by different machines and medical tools. Your name is John Doe. Beside you sits a man who drove you to this place, but who you have only interacted with a few times. At times, the man turns to you to ask you questions, but often he uses words that you don't understand.

After about twenty minutes, a young nurse in colorful scrubs comes in and asks you to lie on the examination table. Having become used to unfamiliar people asking you to do things at the group home, you obligingly lie down on the table. As you lie there, you notice the nurse attaching some sort of bands around your wrists and ankles. Feeling a little uneasy, but trusting that she knows what she's doing, you remain silent. "Okay," she says as she wipes your hand with an alcohol swab, "this will only hurt for a moment." Quickly, the nurse pokes a needle into your hand and tapes it down.

"Ouch!" you protest, still unsure why this is happening. You had visited the doctor before, but nothing like this had ever happened. As you lie there, you begin to feel nervous and hot. Sweat beads down your forehead to the back of your neck. Your heart begins to race. "Ahh!" you gasp, "No!"

"It's okay, Mr. Doe. We are just running some tests. No one is trying to hurt you," the nurse states, smiling.

*What is happening?* Your heart is racing! It feels like it's going to beat right out of your chest. You are hot, so hot!

“Ahh!” you scream as you try to sit up, but the restraints the nurse has attached keep you from raising your arms. You feel faint. Everything is happening so fast! Suddenly, the room is dark...

## 1.2 JUST A SIMPLE STRESS TEST

Though hypothetical, your experience was much like that of the real John Doe. Mr. Doe lives in a group home. He is fifty four years old with moderate mental retardation. What Mr. Doe experienced was a drug induced stress test. Since the physician was unsure as to whether or not Mr. Doe would be able to participate in the stress test by running on a treadmill, he asked Mr. Doe and the head of the group home, who is legally able to serve as a guardian,<sup>1</sup> if Mr. Doe would participate in the drug induced diagnostic test. It is unclear whether or not the cardiologist assumed that Mr. Doe was competent and accepted his consent as a fully informed consent, or whether the group home supervisor's consent had been accepted as the surrogate decision in this case, but the result was that Mr. Doe did undergo the stress test, but did not understand the nature and effects of that test prior to the experience.

For many of us, this may sound familiar. Oftentimes, when we visit the doctor, there are many other things going on in our lives. Among the things that might be distracting us are thoughts about obligations at work, an argument we had with a friend, or emotions we are experiencing because of the malady for which we have scheduled the visit. As we will see in Chapter 5, the diagnosis, mental or emotional state of the patient, and many other factors affect

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<sup>1</sup> See Mental Health and Mental Retardation Act of 1966, 50 PA. STAT. § 4417 (2006).

the determination of whether or not a patient is competent to make an informed decision about his or her care. So what makes Mr. Doe's visit different? Mr. Doe has moderate mental retardation. This fact alone raises the question of competency to make medical decisions much sooner than it would have been raised for many people without mental retardation, if it even would have been raised at all. But when that question is raised, there is rarely a consideration of whether or not there is a way to help Mr. Doe to understand the situation and become informed. Rather, the current system of medical decision making encourages the physician to look for a surrogate decision maker for Mr. Doe.<sup>2</sup> Although it has been suggested that the patient for whom the decision is being made should be informed of the effects of the procedure on that patient at the very least,<sup>3</sup> the reality is that, often, constraints on the physician and other medical staff render it nearly impossible to accomplish while also having time to perform the indicated procedure. The result is that the patient may feel demeaned, demoralized, and disregarded while remaining confused about why his or her body has been violated.

"They murdered me!" Mr. Doe groaned as he threw down his fork on the table. We had just returned from an uneventful visit to the cardiologist.

"I'm sorry, Mr. Doe, what did you say?" I asked. Mr. Doe grasped his chest and threw his head into his other hand that was propped up by his elbow on the table.

"They murdered me!" he moaned. He looked as if he were in severe pain and I wasn't sure what to do.

"Who murdered you, Mr. Doe?" I asked.

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<sup>2</sup> See *infra*, CHAPTER 5, *The Process of Assigning a Surrogate Decision Maker*.

<sup>3</sup> President's Comm'n for the Study of Ethical Problems in Medicine & Biomedical & Behavioral Research, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 94 (1982) ("It may still be appropriate to inform such patients of the nature of their situation and to seek to involve them in the decision making process, even when they do not have the capacity to make legally binding decisions.").

“They did!” he responded. He pointed to his arm and grumbled a few things that indicated to me that he was again speaking about his long since passed visit where he underwent the drug induced stress test.

“Do you mean the doctors, Mr. Doe?” I asked. He nodded and began to cry. He sighed a few deep sighs as if he was trying to purge the pain he felt from that time. His sighs seemed almost involuntary, as there would be a long pause then a quick up-down of his whole body as his head nestled down further into his hand.

As Ann, the supervisor, and Bonnie, the brand new community living specialist (CLS),<sup>4</sup> entered the room with their lunches, Mr. Doe raised his head from his hand and sat up as if trying not to show his pain. The women had noticed his sadness, however, and asked what was wrong. Instantly, his head returned to his hand and the sighs recommenced.

“I think he’s upset about the doctor’s visit,” I answered.

“They murdered me!” he yelled.

“Oh, John, you’re okay. No one murdered you. You had a stress test years ago. Nothing happened today, *did it?*” the supervisor responded.

“No,” he sobbed.

“Hey, John! You don’t have any salad dressing on that salad. Here – take some of this,” the CLS said cheerfully. Mr. Doe poured a bit of dressing on his salad then stabbed at his meal. He ate few bites then pushed it away.

“Are you full?” Bonnie asked. He nodded.

“Okay,” she said.

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<sup>4</sup> A community living specialist is a person who provides care and oversight for individuals living in a group home. These specialists may also be referred to as caregivers.

As the two women commenced eating their lunches and jabbering about shopping and day-to-day things, I picked up my sandwich and ate as if going through the motions; my appetite was gone.

After lunch, Ann explained to me that she was not sure what had happened to Mr. Doe the day he visited the doctor to undergo the stress test. She had been unavailable and one of the alternate caregivers had accompanied him. Now, she said, they were contemplating scheduling another one. Mr. Doe had refused at the visit.

“John, if I stay there with you and hold your hand the *whole time*, will you do it?” she had asked him sweetly on the way home from the visit.

“Okay,” he said, “but only if you’re there with me.”

### 1.3 DEFINING THE DISENFRANCHISED

Although a large proportion of, if not, all individuals with intellectual disabilities have undoubtedly been discriminated against in some way, this thesis aims to bridge a gap in medical decision making for one particular segment of that population; adults with moderate, mild to borderline mental retardation (“M-BMR”). There are special reasons why the focus remains on adults with M-BMR: First, having attained the age of majority in the United States (i.e., individuals who are at least eighteen years of age), these adults have a legal right to expect their autonomy to be respected.<sup>5</sup> Second, fewer ethical dilemmas arise when contemplating the

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<sup>5</sup> U.S. CONST., amend. XXVI, § 1 (providing for citizens of or over the age of eighteen the right to vote); *See also Parham v. J.R.*, 442 U.S. 584, 602 (1979)(noting that the parents are presumed to have “what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions.”).

autonomous decision making power of an adult.<sup>6</sup> Third, recent studies suggest that the autonomous decision making abilities of adults with M-BMR vary, but are not completely absent, depending upon the particular individual, the severity of the illness, complexity of the treatment options, and many other personal and emotional factors just as they do with the general population.<sup>7</sup> Each of these reasons will be discussed in depth below.

Recent trends in social values and in guardianship reforms that require the autonomous decision making power of a partially incapacitated individual to be promoted through judicial preference for the “least restrictive alternative” indicates that the medical profession, whose values also revolve around the well-being and autonomy of the patient, should follow suit. Adults with M-BMR are a population that has not yet enjoyed the right to make their own medical decisions in many circumstances where, if appropriate decision making supports were provided (such as the personal assistant program and collaborative decision making approach to medical decision making recommended in this thesis), they would have the potential to enjoy such right. To understand this, we must first understand who adults with M-BMR are.

In general, mental retardation is defined as a “disability” that manifests before age eighteen and is “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.”<sup>8</sup> The American Association on Intellectual and Developmental Disabilities (AAID), formerly

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<sup>6</sup> Of course, there is the concern of the intellectual age that psychiatrists or other physicians have determined that the individual has reached. However, one of the main concerns with allowing children to make their own decisions is lack of experience due to the amount of time they have lived. Adults with M-BMR have lived longer and experienced more. *See infra*, page 10-11 discussing this topic.

<sup>7</sup> Christine Cea & Celia Fisher. *Health Care Decision-Making by Adults with Mental Retardation*. 41 MENTAL RETARDATION 78-87, 84 (2003).

<sup>8</sup> American Association on Intellectual and Developmental Disabilities (AAID). *Definition of Mental Retardation*, AAMR, at [http://www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml) (last updated Mar. 11, 2005).

American Association on Mental Retardation (AAMR), lists five assumptions that must be made in order to apply the definition:

- 1.) Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture,
- 2.) valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors,
- 3.) within an individual, limitations often coexist with strengths,
- 4.) an important purpose of describing limitations is to develop a profile of needed supports, and
- 5.) with appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

The AAID further expands its definition by explaining that mental retardation is not something you have (e.g. “I have brown eyes”), nor is it something you are (e.g. “I am tall”), nor is it a medical or mental disorder; it is a “state of functioning” that represents the “‘fit’ between the capabilities of individuals and the structure and expectations of their environment.”<sup>9</sup> It is important to note that the AAID has altered the definition of mental retardation to account for environmental and cultural inadequacies as well as to emphasize that the abilities of the individual will improve with “appropriate personalized supports over a sustained period.” These topics will be discussed in greater detail in subsequent areas of this thesis.

Although the AAID has made recent changes, current regulatory schemes and health guidelines have not yet embraced the concept of mental retardation being an individual limitation further hampered by social and environmental factors. Therefore, the population this thesis

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<sup>9</sup> American Association on Intellectual and Developmental Disabilities (AAID). *Definition of Mental Retardation*, AAMR, at [http://www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml) (last updated Mar. 11, 2005).

refers to is defined in more standard medical and legal terms. From both the medical standpoint, and from social security eligibility guidelines, the basic definition is the same: An individual with mental retardation is defined as someone with “significantly sub-average general intellectual functioning” (an intelligence quotient (IQ) below seventy) who also has significant limitations in at least two adaptive skill areas and such intelligence and functional limitations manifested themselves before the age of eighteen.<sup>10</sup> For SSI purposes, the severity of the impairment is met when a) the individual depends on others for personal needs (e.g., eating, dressing, bathing, toileting) and is unable to follow directions, b) the individual’s verbal, performance or full scale IQ is 59 or less, c) the individual’s verbal, performance, or full scale IQ is 60 through 70 and physical or mental impairment limits work functioning, or d) the individual’s verbal, performance or full scale IQ is 60 through 70 and the impairment inhibits/restricts at least two of the following: (1) activities of daily living, (2) social functioning, (3) concentration/persistence/pace, or (4) the individual decompensates repeatedly for extended time.<sup>11</sup>

Although mental retardation is defined as an intelligence limitation coupled with a functional limitation, further subdivision of the severity of mental retardation is made using only IQ. For purposes of this thesis, we shall refer to the World Health Organization’s (WHO) classification as follows:

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<sup>10</sup> Supplemental Security Income for the Aged, Blind, and Disabled, 20 C.F.R. § 416 (1982), *reprinted as amended in* 20 C.F.R. § 416 app. 1 to subpart P at 12.05 (2007). *See also* American Psychiatric Association. DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (4<sup>th</sup> ed. 1994).

<sup>11</sup> Supplemental Security Income for the Aged, Blind, and Disabled, 20 C.F.R. 416 (1982), *reprinted as amended in* 20 C.F.R. 416 app. 1 to subpart P at 12.05 (2007).

**Table 1: WHO Classification of Mental Retardation**

<b>Terminology</b>	<b>Intelligence Quotient</b>
Profound	< 20
Severe	20 – 35
Moderate	35 – 50
Mild	50 – 70
Borderline	70 – 85

The proposal anticipated in this thesis loosely refers to adults with an IQ of 35 to 85 as the target population, recognizing that functional abilities of such individuals may influence a medical decision making capacity determination. As classified above, adults with IQs of 35 to 85 will be referred to as adults with M-BMR.

The focus on adults, rather than children, is based on over-generalized common law and philosophical notions<sup>12</sup> that adults are presumed competent while children are presumed incompetent to make most of their own medical decisions.<sup>13</sup> In Jonathan Will's thesis discussing the dangers of applying the mature minor doctrine to children's refusals of life-saving or sustaining medical treatment based upon religious beliefs, he explains that the presumption that children are incompetent is based on the assumption that children "lack the 'maturity,

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<sup>12</sup> Children, often referred to as minors, are deemed competent, in many states, to make some medical decisions, such as consenting to use of a form of contraception, or consenting to treatment for venereal diseases. In depth discussion of these exceptions, however, is outside the scope of this thesis. For a brief discussion of these exceptions see Jonathan Will. *My God, My Choice: The Mature Minor Doctrine and Adolescent Refusal of Life-Saving or Sustaining Medical Treatment Based Upon Religious Beliefs*. (2004) (unpublished M.A. thesis, University of Pittsburgh) (on file with the University of Pittsburgh Library). A few of the instances where adults are deemed incompetent to make their own medical decisions will be discussed in Chapter 5.

<sup>13</sup> See Allen E. Buchanan & Dan W. Brock. DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING. 216-59 (1989) (discussing the reasons why children should not be considered competent to make their own medical decisions).

experience, and capacity for judgment necessary to make life's difficult decisions."<sup>14</sup> Indeed, Allen Buchanan explains in his oft-cited work, Deciding for Others: The Ethics of Surrogate Decision Making, that although self-determination and well-being are the primary values that physicians should be concerned with when questioning the medical decision making capacity of the adults or children, children have not experienced enough in life, and their aims, values, and commitments have not been challenged enough to have fully developed into "ultimate determinants of [their] well-being."<sup>15</sup> Although there are many instances where children's competence to provide an informed medical decision is accepted in legal and medical practice,<sup>16</sup> the proposal provided in this thesis may inform issues concerning children, including those with M-BMR, but will not directly apply to children with M-BMR.

Due to current medical decision making standards, adults with M-BMR often fall through the cracks when it comes to promoting their autonomy, or (at the very least) promoting their human dignity and well-being. Illustrations of this will follow in the chapters to come. Often adults with M-BMR who may have the capacity to make certain types of medical decisions, but perhaps not all medical decisions, are deemed incompetent to make those medical decisions, or are seen as competent when they do not fully comprehend the nature of their diagnosis, the treatment options, or the risks and benefits of such treatments. It is these patients, patients within the grey area of medical decision making, an area where IQ is less than "normal," but preferences, values, and desires of the patient might be obtainable whom this thesis addresses.

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<sup>14</sup> Will, *supra* note 12 (citing Elizabeth S. Scott, *The Legal Construction of Adolescence*, 29 HOFSTRA L. REV. 547, 558 (2000)).

<sup>15</sup> Buchanan, *supra* note 13, at 227.

<sup>16</sup> Many states have adopted a form of the mature minor doctrine, and many states allow for a child's consent to suffice in situations such as those that involve treatment for venereal disease, contraceptives, mental health, etc. See Will, *supra* note 12.

The most important adults with M-BMR that the proposal in this thesis is directed toward are those adults with M-BMR who have not had guardians appointed for them. These adults have the greatest potential for benefiting from the proposed program since they have not yet lost their autonomous decision making power in any way. Additionally, however, focus will be directed toward adults with M-BMR who have “non-bonded” guardians (i.e., guardians who are unrelated to the patient) as well as adults with M-BMR who live in group homes or institutions. Non-bonded guardians, as explained by Robert Veatch, are total strangers who have been appointed by the court or have “stepped in” as a part of their role of holding public or private office.<sup>17</sup> Bonded guardians, on the other hand are adults who had a pre-existing relationship with the ward. Bonded guardians can be related by blood, or non-related friends or caregivers.

Although the potential for abuse and coercion are present with both bonded and non-bonded guardians, the societal value of preserving the family bond creates a preference weighing on the side of greater scrutiny toward non-bonded guardians.<sup>18</sup> Veatch expresses that this ideology would also favor the family bonded guardian over a non-familial bonded guardian in most circumstances.<sup>19</sup> We will see, however, that societal influences and conflicting family interests have historically played a role in loosening the bond between the family and the individual with mental retardation that American tradition typically favors in other instances. Regardless of whether or not promoting the familial bond is an honorable value, as a practical matter, applying the proposal contained in this thesis to health care visits that involve family bonded and non-family bonded guardians may still be appropriate or allowable in order to reduce

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<sup>17</sup> Robert Veatch, *Limits of Guardianship Treatment Refusal: A Reasonableness Standard*, 9 AM. J. L. & MED. 427, 441-42 (1984).

<sup>18</sup> *Id.* at 442 (discussing the importance of the family bond in society and also stating that “in making the treatment decision, bonded guardians should be allowed greater discretion than non-bonded guardians”).

<sup>19</sup> Veatch notes that the family bonded-guardian should, however, take into account the thoughts of the non-familial friend or caregiver when applying the substituted judgment standard and that if the two opinions greatly differ, there should be a judicial resolution. *Id.* at 446.

confusion or bias as to which adults with M-BMR should be accompanied by a personal assistant, thus expediting medical visits. It is important to note that the personal assistant program proposed in this thesis does not intend to replace any party in the medical decision making process; it merely offers additional support and advocacy for adults with M-BMR so that these adults are able to become more involved in their own health care decisions. Applying this program to health care visits that involve bonded guardians is recommended but is open to the discussion between hospital ethics committees and policy makers, using the insights of physicians, families, and caregivers.

Focus on individuals living in group homes or institutions arises out of the tenuous nature of the relationship between the caregiver or transporter of the individual and that individual. According to the Allegheny Disability Services Alliance, the “turnover rate for Pennsylvania direct care workers in community-based programs [was] 42%” in 2001.<sup>20</sup> This indicates a great likelihood that important relational bonds with staff are lacking within such living conditions.

The proposal argued for in this thesis does not apply to individuals who may be deemed incompetent to make medical decisions because of a present state of unconsciousness. Although there is a need to promote the autonomy of such individuals, legal guardianship or other forms of surrogate decision making may be the most appropriate means for doing so.

Adults with severe or profound mental retardation are also outside the scope of this thesis. Although it cannot be definitively assumed that individuals with severe<sup>21</sup> or profound mental retardation are *always* incapable of making informed medical decisions because of the

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<sup>20</sup> Allegheny Disability Services Alliance (ADSA). *In Our Own Words: Consumers, Families and Workers Speak Out on the Workforce Crisis* (ADSA, 2001).

<sup>21</sup> Adults with severe mental retardation could be considered, but due to the lack of adequate research as to the decision making abilities of these individuals, discussion of involving of such individuals is best left up to those most closely connected with the individual; often this would be parents, caregivers, and medical community. This notion is likely to change as research of the decision making abilities of adults with severe mental retardation progresses.

lack of research on this topic, common experience and discussion of the lack of decision making abilities of these individuals causes me to exclude them from the present discussion with a recommendation that future authors of works similar in substance to this thesis re-explore the trends in research regarding individuals with severe or profound mental retardation before continuing to exclude them.<sup>22</sup>

It must be recognized, however, that excluding adults with severe or profound mental retardation in this discussion has no impact on the current procedures of determining their medical decision making capacity. If this proposal were employed in health care facilities, providing a personal assistant for health care visits involving adults with severe or profound mental retardation may be necessary to confirm that the patients are indeed incapable of making the informed medical decision at hand. Therefore this thesis may apply to adults with severe or profound mental retardation by default. Keeping this in mind, we will embark upon an exploration of American tradition to better understand why our own medical decision making abilities are so valued.

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<sup>22</sup> Until such time, Norman Cantor's efforts in defining the inherent human dignity and worth of such individuals may prove useful to scholars interested in researching surrogate decision making for individuals with profound mental retardation. See Norman Cantor. MAKING MEDICAL DECISIONS FOR THE PROFOUNDLY MENTALLY DISABLED 26 (2005) [hereinafter Cantor, MEDICAL DECISIONS]; See also Cantor, Norman. *The Bane of Surrogate Decision Making: Defining the Best Interests of Never-Competent Persons*. Rutgers U. School of Law (Newark) Faculty Papers. Paper 24 (2004) at <http://law.bepress.com/rutgersnewarklwps/fp/art24> (last visited November 2006) [hereinafter Cantor, *Bane*].

## CHAPTER 2: INDEPENDENCE AND PERSONHOOD: AN AMERICAN TRADITION

Americans value independence, autonomy,<sup>23</sup> and individualism. To gain respect from other citizens and to feel that we are living up to our true potential as people,<sup>24</sup> we express our individuality in many ways; one way is by making our own decisions.<sup>25</sup> Medical decisions, which affect our lives in many ways, are some of the most important decisions that we have to make.<sup>26</sup> Expressing such individualism is a right of all persons in our society. But how do we define personhood? What makes us persons? Are all human beings also persons? Although there has long been a philosophical debate over whether all living human beings have obtained full personhood,<sup>27</sup> for the most part,<sup>28</sup> legislation and judicial opinions tend to imply that all

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<sup>23</sup> See Bruce J. Winick. *On Autonomy: Legal and Psychological Perspectives*, 37 Vill. L. Rev. 1705, 1705-08 (1992).

<sup>24</sup> There have been several philosophical schools of thought as to whether or not individuals with mental retardation have attained full personhood. Although it is important to recognize that these varied schools of thought exist, discussion of them is outside the bounds of this thesis. This thesis focuses on a more humanitarian approach rendering all human beings, regardless of their ability to express futuristic goals or rationality, persons. This notion of personhood rings true when considering rights under the Constitution of the U.S. See U.S. CONST. amend. XIV, §1. See also Cantor, *MEDICAL DECISIONS*, *supra* note 22 at 26 (arguing that “all humans have full legal status and virtually all humans have full moral status”); *RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF*. (Cationa MackKenzie & Natalie Stoljar eds. 2000); *But see* Buchanan, *supra* note 15 at 152-89; *HEALTH LAW* 1138-40 (Barry R. Furrow et al., ed., 5<sup>th</sup> ed. 2001); Peter Singer. *RETHINKING LIFE AND DEATH*. 162 (1994) (quoting John Locke’s definition of “person” as “A thinking intelligent being that has reason and reflection and can consider itself as itself, the same thinking thing, in different times and places.”).

<sup>25</sup> Tom L. Beauchamp and James F. Childress. *PRINCIPLES OF BIOMEDICAL ETHICS* 57 (5<sup>th</sup> ed. 2001).

<sup>26</sup> David J. Rothman *STRANGERS AT THE BEDSIDE* (1991).

<sup>27</sup> Although discussion of this topic would be a voluminous endeavor, a few ideologies (oversimplified and broadly described) are as follows: Buchanan and Brock discuss some of the most commonly accepted conditions for a human being to be defined as a person: 1) The ability to feel pleasure and pain, 2) the ability of recognizing oneself as existing over time (i.e., knowing that one has a past and future, in addition to a present, self), 3) the ability to reason for or against acting (i.e., judgment to inhibit impulses in some instances), 4) the ability to act in purposeful sequences, and 5) the ability to have relations with other people. This definition of personhood considers high intellectual functioning, or cognitive abilities that not all human beings exhibit, as the distinguishing factor between persons and non-persons. I will call this the “cognitive approach.” While philosophers who accept some form of

human beings born within the United States' borders are "persons" protected by the laws of this country.<sup>29</sup>

The Fourteenth Amendment of the U.S. Constitution protects all "persons" born or naturalized in the United States from deprivation by state governments of "life, liberty, or property, without due process of law" and provides such persons with "equal protection of the laws."<sup>30</sup> The Fifth Amendment imposes similar restrictions on the federal government.<sup>31</sup> Within these amendments are the embodiment of autonomy-based rights. When drafting the Constitution, the framers believed in limiting government and promoting individual freedom and

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the cognitive approach do not often believe that all humans are persons, they do often accept that humans, and animals for that matter, maintain some amount of moral value. Other philosophers utilize faith-based values to argue that all human beings are persons. For example, the book of Genesis states that all human beings were created in the "image of God" and, therefore, hold a divine-like status distinguishing them from other animals. Although the divine-like qualities are sometimes interpreted as high intellectual ability, the fact that humans generally possess these qualities is enough to render *all* humans persons. Norman Cantor, in his book discussing medical decision making for the profoundly mentally disabled, provides practical reasons for donning individuals with profound mental retardation with full moral status regardless of their personhood. Among these reasons are emotional sentiments that we feel for our own kind (e.g. "We find it revolting to even think about killing a newborn baby whose anatomical features are so like our own"), enhancement of other persons' emotional lives (i.e., personal attachments), to serve as a symbol of the "sanctity of human life," and to ensure that no arbitrary line is drawn to discriminate against particular helpless individuals. Cantor's notions are important to remember when considering the importance of respecting all human beings' inherent dignity (including unconscious individuals, children, and individuals with any form of mental retardation) and human rights, such as freedom, justice, and privacy. Human dignity and human rights violations have a much higher threshold than moral obligations due to all persons. With respect to adults with M-BMR, personhood might be questioned in different moral philosophy circles, but in medical practice, the question is most commonly answered using the principle of autonomy. Autonomy and rationality (ability to reflect and reason) are two other principles upon which philosophical definitions of personhood have been based. These concepts are most commonly seen in medical contexts and underlie the legal and ethical requirement of informed consent. Autonomy is discussed throughout this thesis. See Buchanan, *supra* note 13 at 29-32 and at 159 (citing J. Feinberg, *The Problem of Personhood* CONTEMPORARY ISSUES IN BIOETHICS 108-16 (T.L. Beauchamp & L. Walters, eds., 2<sup>nd</sup> ed. 1982). 108-116 (1982); M.A. Warren. *On the Moral and Legal Status of Abortion*. CONTEMPORARY ISSUES IN BIOETHICS 25-60 (Beauchamp & Walters eds., 2<sup>nd</sup> ed. 1982). Cantor, *MEDICAL DECISIONS*, *supra* note 23 at 17-19; *RELATIONAL AUTONOMY*, *supra* note 25; *But see* HEALTH LAW 1138-40; Singer, *supra* note 25 at 162.

<sup>28</sup> See Jennifer Rebecca Levinson, *Symposium: Of John Brown: Lawyers, the Law, and Civil Disobedience*, 54 Ala. L. Rev. 985, 1025 (2003) (noting a time when women, like slaves, had no legal personhood).

<sup>29</sup> See *Roe v. Wade*, 410 U.S. 113 (1973). See also *Planned Parenthood v. Casey*, 505 U.S. 833 (1992) (The Supreme Court protected the privacy of the mother, utilizing an underlying principle of protection of personhood (and right of self-determination), when it stated, "[A]t the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State." It is important to note the Court's use of "human life" in protecting the individual's self-determination and personhood.).

<sup>30</sup> U.S. Const. Amend. XIV, § 1.

<sup>31</sup> U.S. Const. Amend. V.

independence, or autonomy.<sup>32</sup> This ideology is also present in the Bill of Rights<sup>33</sup> and, in the medical context, in the American Hospital Association's Patient's Bill of Rights.<sup>34</sup> Although the Patient's Bill of Rights does not establish legal rights,<sup>35</sup> it has been adopted into law in many states, including Pennsylvania.<sup>36</sup>

The autonomy-based right of self-determination has been confirmed in the context of medical decision making for both competent and incompetent patients.<sup>37</sup> Although many decisions for incompetents are often rendered through a surrogate decision maker, recent guardianship reforms have emphasized that a preference for the "least restrictive alternative" to guardianship should be employed so as to further the individual's own autonomy to the greatest extent possible.<sup>38</sup>

Respect for and promotion of an individual's autonomy may be only one of the legal and moral principles upon which we base our laws and actions, but it should be emphasized where the individual is part of a population that has historically been discriminated against and whose independence has been trodden upon. Adults with intellectual disabilities, among whom are adults with M-BMR, constitute one such population. From eugenic approaches to involuntarily sterilizing the "feeble-minded," to institutionalizing "mongoloid" children,<sup>39</sup> adults with intellectual disabilities have suffered from discrimination.

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<sup>32</sup> Winick, *supra* note 23 at 1708.

<sup>33</sup> The first ten Amendments to the U.S. Constitution are known as the Bill of Rights.

<sup>34</sup> Section 5 and 6 of the Patient's Bill of Rights provide for full informed consent and the right to refuse treatment. The notion that the patient has a self-determinative right to decide what is medically right for themselves, what their own autonomous choice is, underlies these rights.

<sup>35</sup> John F. Harty, *Patient's Bill of Rights*. 2 HOSPITAL LAW Ch. 1, 1 (1981).

<sup>36</sup> 28 PA. CODE §§ 103.21-103.24 (2007).

<sup>37</sup> See *In re Quinlan*, 355 A.2d 647, 670 (N.J. 1976); *Cruzan v. Harmon*. 760 S.W.2d 408, 416-17 (Mo. 1988); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1976).

<sup>38</sup> See *infra*, Chapter 5, Section 5.2.3 *The Least Restrictive Alternative: A Failed Means of Balancing Autonomy and Beneficence*.

<sup>39</sup> Chris Burke & Jo Beth McDaniel. A SPECIAL KIND OF HERO. 31-32 (1991) (A story of Chris Burke, former star of the hit television show "Life Goes On." In the story, Chris' mother recalls her physician's straightforward advice

Recognizing the inherently unequal restrictions that guardianship places on the autonomy of adults with M-BMR (who could potentially provide informed consent if offered adequate supports), as well as the ever-present potential for guardianship abuse, state legislatures attempted to improve the system of decision making (including medical decision making) by implementing statutes that called for judicial preference of the “least restrictive alternatives” to guardianship. Current medical and judicial practice, however, has changed little. This results from the history of discrimination that persists today, an inadequate understanding of the decision making abilities of adults with M-BMR, and a lack of adequate supports for the varied decision making abilities of these individuals. Our American tradition requires that alternative methods of promoting the autonomy of adults with M-BMR be considered, in view of the fact that the originally stated goals of limited guardianship have not been met.

Implementing a personal assistant program for all health care visits involving adults with M-BMR provides a practical means of balancing the social inequality that these individuals have experienced while promoting the autonomous medical decision making power they have yet to be allowed to realize. Embracing a collaborative decision making approach that acknowledges the interconnectedness of each individual with his or her physician, family, friends, and other caregivers, and respects the autonomy and/or professional expertise of those individuals, further promotes the involvement and decision making abilities of the patient with M-BMR with regard to his or her own medical care.

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after Chris was born: “Put him in an institution...Forget you ever had him. It will be the best thing for you and for your family.”).

## CHAPTER 3: THE PROPOSAL: A TWO-STEP APPROACH

### 3.1 THE PERSONAL ASSISTANT

Currently a personal assistant program for adults with intellectual disabilities is not available. For this reason, it is important to understand what is being proposed. A personal assistant, in this context, is a disinterested third party trained and experienced in working with individuals with disabilities (specifically intellectual disabilities). To be a “disinterested third party” the personal assistant cannot have personal or financial ties to the families, physicians, residential facilities, or medical institutions involved in the individual’s care.<sup>40</sup> This disinterested third party should be trained and well-versed in biomedical ethics<sup>41</sup> and cultural diversity and

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<sup>40</sup> The fact that the personal assistant does not have financial ties to the health care facility or the families raises many questions about who the personal assistant would report to, where the funding for personal assistants would originate from, and how the personal assistant would be made aware of the patient’s health care visits. Although the answers to these questions would require extended discussion that is outside the scope of this thesis, one potential organization that could be considered for funding and supervision, and scheduling is the Department of Health and Human Services (DHHS). DHHS is the primary agency of the United States government that promotes the health and well-being of all American citizens. Therefore, it should be considered and included when discussing practical implementation of the personal assistant program.

<sup>41</sup> Ethics is an important component of the training because, in addition to serving as a type of informational translator, the personal assistant also serves as an advocate for the patient. This being so, the personal assistant must recognize the competing values and interests of the patient, the physician, and the parent or guardian. These interests may overlap each other in some ways, but it is important to recognize that they are internal to the decision being made. The personal assistant would serve as a bioethicist in the sense that she would assist the parties in acknowledging their own interests that are playing a role in the decision and would help them to come to a collaborative decision with those interests in mind. Those that do not have the best interest of the patient at heart should be minimized. Involving the patient with mental retardation to the greatest extent possible is one way of minimizing these. To understand these competing interests, consider the following example:

Tom keeps hitting himself in the head. Though it was later determined that he was only hitting himself in the head when he was constipated, he had been given several different drugs to extinguish the behavior. The reasons for the prior misdiagnosis and treatment might have been partly due to the physician’s values and interests, the caretaker’s values and interests, the patients values and interests, or a combination.

should also have had some clinical experience in the medical field so that he or she has a basic understanding of common medical roles and procedures.

The personal assistant would perform multiple functions, not unlike many other professionals in the medical field and business world. First, the personal assistant would be an advocate for the patient. She or he would be someone who could ensure that the patient is

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Possible physician values and interest could have been a) that medication will alleviate the symptoms (this is something that seems to be drilled into medical students' minds throughout medical school), b) lack of time (perhaps the physician was concerned about time spent with each patient and didn't take the requisite time to explain fully or to fully understand what the patient was trying to communicate; physician also might not have questioned the caregiver enough – perhaps a longer discussion with the caregiver into the times of the day when Tom was hitting himself might have helped the physician determine the cause earlier), concern about the caregiver and his or her interests (Although this would not be an ethically permissible reason for treatment, it's quite possible that it happens even without the physician realizing that is what she is doing – family-centered value approach).

Potential caregiver interests could have been a) lack of time, b) other family members, or c) convenience of treatment (Providing a pill to the individual is easier than making behavioral alterations).

A personal assistant trained in considering cultural and behavioral symptoms might have been able to help. A personal assistant would have been able to ensure that a full discussion about the possible causes was discussed with the patient and the caregiver to the greatest extent possible.

We may also consider an example as this circumstance with Sally: Sally is twenty-eight and has a habit of masturbating in bed. She does this during her period as well. The staff supervisor requests a Depo-Provera shot to reduce the frequency of the patient's periods because her practice is a "mess to clean up."

Here, the caregiver's interests seem to have been the convenience for nursing and cleaning staff – putting Sally on Depo means less time spent cleaning up after Sally. The potential benefits to Sally could be less frequent periods (if they are bothering her, which we are not sure that they were), but the potential harms are weight gain, headaches, irregular periods (harder to administer pain relief prior to periods if the start of the period varies – in this case, we know that Sally has regular periods right now without the Depo. It is recommended that she be given pain relief three days prior to the start of her period and at least the first three days of her period), fatigue, abdominal pain, and decreased sexual desire (As in historical sterilization cases, this might be seen as good by the staff, but who are they to say that an autonomous human being's natural desires should be constrained?), depression, darkening of skin on upper lip, under eyes, and on forehead (chloasma). This case seems to parallel many of the prior sterilization cases we discussed earlier. Additionally, Sally's autonomy is not promoted and the costs and benefits weighed should only be those of the patient, Sally, not third parties.

It's possible that the guardian/family member/facility staff member might not be able to recognize the difference between treatments that are in the best interests of the patient and those that are merely in the best interests of the facility. The physician, though sometimes notes and addresses these, might not always have the appropriate amount of time to delve deep enough into the circumstances in order to determine the true interests that are being served (perhaps the communication is such that it appears to be a request in the best interests of the patient, but when further analyzed, is truly in the best interests of the third party). There may be other issues at work, such as in this case where the staff member was also considering the danger that a patient might be placing him or herself in, or others in (Ex. Lunging and biting at the driver of the residential facility's van). The personal assistant could help to distinguish between behaviors that should be treated (those that endanger the patient or others) and those where the physical costs (i.e. Side effects) might outweigh the benefits (Sleeping through the night rather than getting up to walk around – this type of medication might be provided for the convenience of the night staff). Additionally, the personal assistant could discuss the need for promoting the autonomy of the patient. At the same time, it would be desired that the personal assistant would provide a human quality to the visit by recognizing the great time, effort and patience that is necessary for someone to care for another person, let alone someone with an intellectual disability (this effort should not be ignored).

addressed during the visit, that time is taken to help the patient understand the discussion, and that the patient's values and preferences are heard. In a sense, the personal assistant would be present to reduce the social stigma that has been placed on individuals with intellectual disabilities perhaps filling a role that some parents feel embarrassed or nervous to fill.

Second, the personal assistant would serve a function akin to that of a translator.<sup>42</sup>

Depending upon the needs of the particular patient, the personal assistant could provide auxiliary aids, pictures, or alternative forms of communication as that person's knowledge about communication and understanding of individuals with mental retardation increases.<sup>43</sup>

Third, the personal assistant could provide emotional support for the adult with M-BMR. Assuming that the personal assistant fills a role similar to a consultant, she would have the freedom to remain with particular patients throughout their medical travels. For those adults with M-BMR who live in group homes or institutions, this more consistent presence would be a welcome change from the high turnover that group home residents experience with their caregivers.<sup>44</sup> Over time, the personal assistant might be able to fill the role that the supervisor of the group home had intended to fill for John Doe the second time he was to undergo a drug-induced stress test. The personal assistant could be there to hold his hand and assure him that all is well.

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<sup>42</sup> See *infra*, Chapter 4, Section 4.4, *Recent Progress in Understanding the Medical Decision Making Abilities of Adults with M-BMR* (providing recent empirical studies that illustrate the potential medical decision making capacity of adults with M-BMR who are provided with various forms of support and communication).

<sup>43</sup> As research increases, there may come a time when these translational services will be required much in the same way that sign language interpreters have been. Discussion of this topic is relevant, but outside the scope of this thesis. See generally *Gillespie v. Dimensions Health Corp.*, 369 F. Supp. 2d 636 (Md. Dist. Ct. 2005) (Plaintiffs have standing to seek injunctive relief under Title III of the ADA where defendant followed a policy of not providing in person sign language interpreters for health care visits). See also *Mayberry v. Von Valtier*, 843 F. Supp. 1160 (E.D. Mich. 1994); *Majocha v. Turner*, 166 F. Supp. 2d 316, 325 (W.D.Pa. 2001).

<sup>44</sup> See *supra*, Chapter 1, Section 1.3 (discussing the high turnover rate of caregivers in the group home setting).

The personal assistant would, in a sense, serve as a mediator.<sup>45</sup> Employing her training in ethics, she could raise questions that illuminate the differing values and interests that each individual holds. For example, by asking each individual what her particular concerns are with a treatment or treatment refusal, the personal assistant could help the family member or caregiver to understand what personal interests are in play, the patient to understand her goals, values and preferences, as well as her relational commitments, and the physician to understand her underlying values and constraints, such as time and individual versus community health approach.<sup>46</sup>

Finally, the personal assistant could also potentially serve as a witness to the discovery that the particular individual is in need of a limited guardian or even a full guardian. However, due to the conflict that this role of the personal assistant poses with the personal assistant's role as an advocate for the patient with M-BMR, utilization of the personal assistant in this manner would be very limited.

The primary role of the personal assistant is that of an advocate for the patient and respect and/or promotion of that patient's autonomy. Personal assistants would be required to recognize this and to practice in a manner consistent with this ethic. There is the potential that physicians, potential guardians, or health care institutions might desire the personal assistant to assume a greater role in determining the necessity of a guardian in certain circumstances. Remaining true to the ethic of advocacy and promotion of the patient's autonomy, the personal assistant may assume a duty of indicating when he or she has exhausted all avenues for communicating with and obtaining the understanding of the patient, but the personal assistant could not and should not be utilized as a means for determining incompetency, or medical decision making incapacity,

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<sup>45</sup> Please note that if true mediation services are necessary, the personal assistant (whose primary duty is to advocate for the patient) would not be the appropriate person for that role.

<sup>46</sup> For further discussion on this topic see *infra*, Chapter 3, Section 3.2.

aside from this duty. Once the personal assistant has presented evidence of her good faith effort to increase the patient's understanding of the diagnosis, treatment procedures, and risks and benefits, as well as her opinion that the particular patient's personal history and experience tends to indicate that allowing more time for further mulling would have no effect, she assumes no additional role in guardianship hearings.<sup>47</sup>

In all cases, the primary roles of advocacy, communication, and support are to be preferred. Disengaging the personal assistant from that role requires an initially high burden of proof that the patient is incompetent, on the part of the potential guardian, including medical testimony of a physician or psychiatrist prior to involving the personal assistant. This will ensure the personal assistant receives the greatest amount of freedom in providing advocacy, communication assistance, and support, in favor of promoting the patient's autonomy, while remaining cognizant of the impact such services are or are not having on advancing the well-being of the patient.

### 3.2 COLLABORATIVE DECISION MAKING: BALANCING AUTONOMY AND WELL-BEING

Autonomy and well-being are moral and legal principles that may conflict with one another in certain circumstances involving adults with M-BMR and medical decision making. Indeed, these principles often conflict when the medical decisions involve adults without M-BMR as well. Adults, whether competent, incompetent, or partially competent to make their own medical decisions, are complex beings with values, aims, and preferences besides those

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<sup>47</sup> Unless, of course, the personal assistant determines that part of her evaluation was inaccurate, or there is further evidence that indicates that another attempt at promoting that patient's medical decision making power is required.

furthering their own well-being.<sup>48</sup> The adult could decide to forgo a blood transfusion based on firm religious beliefs,<sup>49</sup> could decide to forgo costly life-sustaining medical treatment to keep the family from going into debt, or could request that all discussion of his or her illness be only with the adult's children rather than the adult, based on the cultural belief that the children assume responsibility for the parents upon reaching a certain age.

These are just a few examples, but they all indicate ways in which patients exercise their autonomous decision making authority while potentially negatively impacting their health, and possibly their well-being.<sup>50</sup> Adults with M-BMR might make similar decisions, but without a deep understanding of their particular communication abilities or reasoning skills, the decision could be deemed an incompetent one more readily than those of adults without M-BMR. Involving a personal assistant in these instances, and incorporating a collaborative decision making approach could assist in promoting the M-BMR adult's autonomy by increasing discussion with the patient and by helping the physician to understand the communication cues. Providing a personal assistant, and utilizing a collaborative decision making approach, could also promote the well-being of the patient by helping to translate the physician's medical information into information that the particular patient can appreciate and understand and by allowing the patient to be more involved in the decision. Before exploring this further, we must first understand what collaborative decision making entails.

In general, collaborative decision making means to work together in coming to a decision. Most of us make collaborative decisions every day. In the context of health care

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<sup>48</sup> Buchanan, *supra* note 13 at 35.

<sup>49</sup> Beauchamp & Childress, *supra* note 25 at 60 (discussing that adults who are Jehovah's Witnesses might refuse a blood transfusion based on their chosen religious beliefs – Beauchamp and Childress explain that this decision would remain in line with the principle of autonomy based on the fact that the adults chose to be a part of that religion).

<sup>50</sup> See *infra*, Section 3.2.3 (providing examples of autonomous choices that might negatively affect well-being).

decisions, a collaborative decision is one in which the patient, physician, and caregiver attempt to reach a consensus on a given treatment. In reaching the decision, the values and interests of each party are considered, as well as the medical expertise of the physician. With the help of the personal assistant, the varying values and interests might be given different amounts of weight, with the patient's values, interests, preferences and aims as most important.

This method of decision making acknowledges the interrelated nature of the patient's own autonomy, the varying influences that are involved, and the dependence the process has on the information and professional recommendations provided by the physician. The primary goal of the collaborative decision making process is to promote the autonomy of the patient with M-BMR, while also enhancing that patient's well-being to the greatest extent possible. To fully understand this goal, we must explore the meaning of autonomy and well-being, their relation to the goals of medicine, and the potential tension that arises between these two principles.

### 3.2.1 WELL-BEING

Medical decisions are some of the most important decisions we have to make in our lives. Most of the time, we try to make medical decisions that improve or promote our well-being. However, there are times when we don't. Physicians, serving as trusted medical advisors, have a duty in those instances to ensure that we truly know that we are deciding in such a way and that we are in the right state of mind when we do.<sup>51</sup> But what is this well-being that we are to promote?

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<sup>51</sup> The physician's role in ensuring that we truly know that we are deciding in a manner contrary to our well-being arises from their professional duty to promote the goal of medicine that, as stated by the American Medical Association (AMA), is "to promote the art and science of medicine and the betterment of public health." The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." See *infra*, Chapter 5, Section 5.1 (discussing the legal and ethical obligations of physicians to ensure informed consent).

Simply put, well-being has been defined as the “good for persons.”<sup>52</sup> In Deciding for Others, Buchanan and Brock explain that well-being can be broken down into three broad, yet oversimplified, philosophical theories known as 1) the hedonist theory, 2) the preference satisfaction theory, and 3) the ideal theory.<sup>53</sup>

The hedonist theory of well-being claims that “the only thing that is good for [] person[s] is having experiences of a specified, positive sort.”<sup>54</sup> This theory implies that something that makes us happy, or brings us pleasure or satisfaction, increases our well-being. This would mean that health care treatment that creates conscious happiness in our lives would promote our well-being.

The preference satisfaction theory maintains a view that a person’s well-being is promoted when her desires or preferences are satisfied to the maximum extent possible in her lifetime.<sup>55</sup> The example Buchanan and Brock provide is that of Jones: Jones desires for her husband to be faithful. In order for Jones’s well-being to be promoted, all that is necessary is for her husband to be faithful. There is no requirement that Jones’s husband make a conscious effort, or that he even know that Jones has this desire; if Jones’s husband is faithful, regardless of the reason, Jones’s well-being has been promoted. Buchanan and Brock note that the hedonist theory and the preference satisfaction theory are closely linked in the sense that most people prefer to be happy.<sup>56</sup> In this example, however, the hedonist theory would hold Jones’s happiness as the ultimate determinant of Jones’s well-being, regardless of the veracity that Jones’s husband was indeed faithful. So long as Jones *believed* that her husband was faithful, by hedonist theory, her well-being would be promoted.

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<sup>52</sup> Buchanan, *supra* note 13 at 31.

<sup>53</sup> *Id.*

<sup>54</sup> *Id.* (citing R. Brandt. A THEORY OF THE GOOD AND THE RIGHT 246-65 (1979)).

<sup>55</sup> *Id.*

<sup>56</sup> *Id.* at 32.

Finally, the ideal theory sets an objective, rather than subjective, standard for promotion of well-being. If a person were to justify her actions based on this theory, she would first have to determine whether her actions had been considered good or bad using the ideal theory. The problem with this theory, as Buchanan and Brock note, is that the moral philosophers who favor this theory do not agree upon what the ideals are and how those ideals are to be justified.<sup>57</sup> For this reason, the ideal theory appears to be the least useful theory when determining whether an individual's well-being is promoted.

In considering these three theories, a patient or physician might be able to assume that if the patient's choice satisfies her preference and brings happiness to the patient's life, then her choice has promoted her well-being. With regard to a patient's health, often the choice that will make the patient happy, and would be the patient's preference would be to "get better" from whatever ailment it is that the patient has. However, medical decisions are rarely so clear cut.

Most medical treatments involve risks and benefits. Generally, if the benefits far outweigh the risks, then the treatment would be medically advisable. We could consider any choice that is medically advisable, or medically recommended, as a choice that the medical profession might perceive as fitting in the ideal theory of well-being. Therefore, when a patient decides against treatment, or chooses a treatment that is not medically advisable, the physician might need to question the patient's understanding of the consequences of her choice.<sup>58</sup> If the patient is unable to communicate her understanding of the treatment and the consequences of her choice against the recommended treatment, and her underlying preferences and values with

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<sup>57</sup> *Id.* at 33.

<sup>58</sup> This paternalistic role of the physician will be discussed further in Chapter 5.

regard to her choice, then the physician must determine if he is able to provide more information to that patient to increase her understanding, or whether her decision should be overridden.<sup>59</sup>

The idea that a physician has a duty to override the patient's decision indicates a conflict of well-being theories. While the physician's duty has historically arisen from an ideal theory of well-being, the growing focus on autonomy arises out of a preference satisfaction theory of well-being. What collaborative decision making aims to do is bridge the gap between the conflict of the two theories by allowing for a full discussion between the patient and the doctor - an honest, open discussion that balances the struggle of authority. To understand the necessity of balancing well-being with autonomy and considering the values of others, we now look to the role of autonomy in medicine.

### 3.2.2 AUTONOMY AND THE INTERCONNECTED WEB OF RELATIONS

The word *autonomy* finds its roots in Greek; *autos* meaning "self," and *nomos* meaning "rule," "governance," or "law."<sup>60</sup> Autonomy first referred to the "self-governance of independent city-states"<sup>61</sup> but now extends to individuals and their right to choose their own plan for their lives. Although there are varying limitations on this notion,<sup>62</sup> and additional moral principles upon which decisions must also be based,<sup>63</sup> the rationale behind this right of self-governance is that individuals are best suited to determine what will make them happy.<sup>64</sup>

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<sup>59</sup> Buchanan and Brock point out, however, that an individual may be confused or misguided about what will promote his or her well-being. This is especially true with regard to medical decisions, and will be discussed further in Chapter 6, Section 6.1. See Buchanan, *supra* note 13 at 32.

<sup>60</sup> Beauchamp & Childress, *supra* note 25 at 57.

<sup>61</sup> *Id.* at 57-58.

<sup>62</sup> Generally, a person is not allowed to express his or her autonomy in such a way that it brings harm to others, and sometimes the harm the person is allowed to bring to herself is limited as well. See

<sup>63</sup> Beauchamp & Childress, *supra* note 25 at 57 (explaining that the principle of autonomy does not necessarily override all other moral considerations, including beneficence, non-maleficence, and justice).

<sup>64</sup> See Winick, *supra* note 23 at 1755-56 (discussing the theory that the individual is best suited to "chart a course for the pursuit of happiness than is the government.").

There are different ways in which autonomy is defined. Beauchamp and Childress' definition is often cited in the medical context. Beauchamp and Childress focus on autonomous choice, or acts, rather than autonomous persons. Their rationale is that even what other philosophers would call "autonomous people" are sometimes unable to make an autonomous choice due to depression, ignorance, coercion, or a number of other influences. Since this thesis is based on the ability of adults with M-BMR to make autonomous medical decisions, we will focus on autonomous choice as well.

Autonomous choice is 1) intentional, 2) made with understanding, and 3) without controlling influences that determine the choice.<sup>65</sup> A patient expressing autonomous medical decision making power would 1) intentionally choose a treatment, 2) with the understanding of nature of the procedure or treatment, the risks and benefits of that procedure, and alternatives to such treatment,<sup>66</sup> and 3) without controlling or coercive influences. While the notion of understanding will be discussed in Chapter 5, it is important to understand when influences are a part of a person's autonomous choice and when those influences impede the autonomous choice of the patient.

People are uniquely interconnected with their environment. Their lives are made up of relations with other people, animals, things, and beliefs. A person's daily life consists of acts that relate to his or her needs and desires and the needs and desires of others. Each day, a person makes many decisions that consist of intentional acts, made with understanding, but with underlying influences. For example, Mike might decide to buy a coffee rather than a latte because he does not have a lot of money. Mike *really* wanted the latte, but he didn't feel that he could afford it. He has a wife and son at home and they are just scraping by to make ends meet.

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<sup>65</sup> Beauchamp & Childress, *supra* note 25 at 59.

<sup>66</sup> Jessica W. Berg et al. INFORMED CONSENT 53 (2001).

For that reason, he decided not to indulge in his pleasure in order to avoid further financial hardship for the family.

People make some health care decisions in a similar way. We can consider Mike now at a medical visit. He has injured his knee in such a way that his health insurance will cover physical therapy, but it will not cover surgery. Although the physician believes that surgery is the way to go, Mike decides to opt for the physical therapy because it is covered. While money is an influence, the emotional distress that his wife might feel if he opted to pay for the expensive surgery was also an influence on his decision. Most people would not consider these influences coercive or a hindrance to someone's autonomous decision making power.

Coercive influences, on the other hand, are influences that employ "force to gain compliance"<sup>67</sup> or "that deprive[] a person of freedom of choice or substitutes another's choice or desire for the person's own."<sup>68</sup> If Mike's wife threatened to leave him if he chose the surgery or the latte, that might be considered a coercive influence.

No decision, including medical decisions, is completely free from influence. Beauchamp and Childress offer that for the decision to be autonomous, only a "substantial degree of understanding and freedom from constraint" should be necessary.<sup>69</sup> They also note that if too much understanding or freedom from influence is required, it creates a narrow definition of the autonomous choice as being almost completely "independent" and "rational" and, thus, allowing only elite intellectuals freedom to make their medical decisions. Rather, Beauchamp and Childress endorse a relational autonomy approach and agree with relational autonomists that "oppressive socialization" and "oppressive social relationships" should be overturned and

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<sup>67</sup> Dictionary.com. *Coercion*, Lexico Publishing Group, at <http://dictionary.reference.com/browse/coercion> (2007).

<sup>68</sup> *Id.*

<sup>69</sup> Beauchamp & Childress, *supra* note 25 at 59.

autonomy of the oppressed promoted even though their decisions and actions may not be considered fully rational or independent.<sup>70</sup>

In health care decision making, it is important for the physician to understand how dependent the patient's understanding of the diagnosis, treatment, risks, benefits, and alternatives are on the physician's provision of information. This will be discussed thoroughly in Chapter 5. How much information is provided, or in what manner, is often influenced by the physician's own interests and values. An examination of some of the different values and interests that might be involved with regard to medical decisions made by adults with M-BMR helps to understand this.

### 3.2.3 VALUES, INTERESTS, AND SOCIAL INFLUENCES

In addition to conflicting theories of well-being, physicians and patients come from different social and cultural backgrounds and, thus often have different values and interests. A value is "any object or quality desirable as a means or as an end in itself."<sup>71</sup> An interest is something that concerns the patient. As a person ages, her values are tested by different circumstances in her life. Her values might change or strengthen as a result of stresses and circumstances. Interests are changeable as well.

In respecting a person's autonomous choice, we are accepting that the person might base his or her choice on different values or interests than our own. In medicine, some of the physician's values stem from her own social and cultural background, while others extend from her professional experience and obligation as a physician. It is important for a physician to differentiate between the two when advising patients and determining competency. Values that

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<sup>70</sup> *Id.* at 61 (citing Catriona Mackenzie and Natalie Stoljar, *Introduction: Autonomy Refigured*. RELATIONAL AUTONOMY 3-31 (2000)).

<sup>71</sup> Dictionary.com. *Value*, Lexico Publishing Group at <http://dictionary.reference.com/browse/value> (2007).

are personal to the physician have no real place in the medical decision making process while values that arise out of professional duty may. Some of the values that might arise out of the physician's professional obligations are promoting the patient's health and well-being, avoiding unnecessary and costly treatment orders, and promoting efficient medical visits so as to help a great deal of patients.

Patients' personal values, on the other hand, do have a place in the medical visit. The patient's values are also formed and influenced by her social and cultural background. These values might not always put the patient's medical well-being first. For example, an elderly patient might truly value being around family above all else. Her whole life has been based around raising the family and promoting the family unit. When she is told by the physician that her health is such that it requires her to move into a nursing home or to a warmer climate in order to live as healthfully as possible, she may choose live out her days at home even though it might not be considered the "ideal good for persons." In this case, if we were to look at both the hedonist sense of well-being and the preference satisfaction theory of well-being, the decision probably would have promoted her well-being.

However, there are instances where patients' medical decisions, based on their values, do not coincide with well-being in any sense. Consider the same elderly patient, but this time the nursing home is not medically recommended because she has severe stress attacks when around a lot of people she doesn't know. However, she values her family and not being a burden on them. She has come to a point in her life where she cannot care for herself. She chooses to live in the nursing home and suffer with the stress so as not to be a burden on her family. In this case, no one was coercing her into moving into the nursing home. However, she wasn't moving

into the nursing home because she desired to be there, or because it would make her any happier. She held a firm belief in not becoming her family's burden and decided accordingly.

In this case, the physician's professional values tend to conflict with the patient's values. If the only moral obligation on which to base decisions was to promote the autonomy of the patient, then the patient's decision would be accepted without question. However, the physician has a professional obligation to promote the patient's well-being as well. If transferring the patient to the nursing home is going to harm her well-being (e.g., through stress), the physician is obligated to evaluate the patient's decision.

Additionally, the patient's decision is intertwined with the family that she holds dear. Perhaps the patient's grandson had every intention of taking care of his grandmother for the rest of her days. He values his relationship with his grandmother so much that he was willing to take her in and care for her. However, he was not present at the doctor's visit and would not have been allowed to be a part of the visit regardless.<sup>72</sup> His values were not to be considered. If the grandmother had another value of never discussing health-related issues outside of medical visits, then the grandson might never know why his grandmother moved into the nursing home, leaving them both feeling upset by the decision.

Parents, family members, or close friends of adults with M-BMR may have values that are even more intertwined than those of the elderly patient and her grandson. Often, especially in the case of parents, their lives have revolved around that of their child with M-BMR. The health care decisions that the patient with M-BMR makes might impact the parents emotionally, financially, spiritually, or socially. In cases of adults with M-BMR, however, these relations have not always been severed, but instead have often influenced the physician to allow the parent

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<sup>72</sup> The grandson might be able to participate in the discussion if his grandmother consented to his presence and participation.

or caregiver to make the decision for the adult. The reasons this happens will be discussed in coming chapters. This would be akin to allowing the grandson to decide for his grandmother without any input from her at all.

Although families and caregivers may often decide for the adult with M-BMR in a way that promotes her best interest, there are many instances where the family or caregiver's own interests and values influence the decision. For example, Mary gives birth to a child with Down Syndrome in a time when society favored institutionalizing such individuals. Although Mary goes home with the child initially, when the child turns twelve she finally decides – because of the burdens that the child creates on her life, including the social stigma and the frequent medical visits and calls from school - to institutionalize her child.<sup>73</sup> The child does not desire to be institutionalized, but the decision has been made for her. Within a twenty year timeframe, the child has only seen her mother a total of six times.

### 3.3 PROMOTING THE BALANCE: COLLABORATIVE DECISION MAKING

Promoting the autonomy and the well-being of a patient with M-BMR are important parts of medical decision making. As we have seen, however, these two principles may be in conflict at times. Part of the reason that they may conflict could be due to the patient's values and interests or the result of external influences, such as the patient's family's values, social influences, or cultural beliefs. Additionally, the information provided by the physician might not have been explained in a manner that was meaningful to the patient, or was detailed enough.

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<sup>73</sup> See Burke, *supra* note 39 at 31-32 (discussing the common medical practice of recommending that “mongoloid” children be sent straight to an institution after birth). See also *Saikewicz*, 370 N.E.2d 417 (Mass. 1976) (where a sixty seven year old man with profound mental retardation was institutionalized by his parents at age fourteen).

Utilizing a collaborative decision making approach to medical decisions made by adults with M-BMR allows for increased discussion of the various values that are present and influencing the patient's decision, as well as the values of the patient's family or caregivers. Introducing a personal assistant to the visit would ensure the patient is included in the decision to the greatest extent possible. With training in ethics, the personal assistant would also be able to help illuminate conflicting values and interests that might not be appropriate influences on the decision. Through this discussion, and greater advocacy for the patient with M-BMR, the goals of promoting the patient's autonomy (which is inextricably linked with relational influences) and protecting the patient's well-being will be balanced to the greatest extent possible.

## CHAPTER 4: THE RATIONALE

Armed with a basic understanding of what this thesis proposes, we must now return to the reasons why such a proposal is being made. Individuals with mental retardation have endured a long history of discrimination.<sup>74</sup> Over time, societal views have changed,<sup>75</sup> but inequities in the

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<sup>74</sup> Since ancient times, individuals with mental retardation have experienced social stigmatization. Greek and Roman cultures considered individuals with mental retardation as a “burden on society.” Adult and Child, Inc. *Historical and Contemporary Perspectives on Mental Retardation*, COMPREHENSIVE HEALTHCARE FOR EVERY STAGE OF LIFE, available at [http://www.adultandchild.org/poc/view\\_doc.php?type=doc&id=10350&cn=208](http://www.adultandchild.org/poc/view_doc.php?type=doc&id=10350&cn=208) (last visited Feb. 25, 2007). Often, infants born with mental retardation would be killed or sold for entertainment. *Id.* In Western culture, we see terminological illustrations of social stigmatization regarding individuals with mental retardation as “stupid,” “feeble-minded,” or “idiots.” Mary L. Manion. *Mental Retardation as a Western Sociological Construct: A Cross-Cultural Analysis*. 2 DISABILITY, HANDICAP AND SOCIETY 2 (1987). Some of the mistreatment of these individuals was due to cultural and religious beliefs, while other discriminatory acts stemmed from social, political, and scientific norms of the day. *See Id.* For a discussion of this history, see Diane B. Paul. CONTROLLING HUMAN HEREDITY, 1865 TO PRESENT 2-3, 5-7, 46 (1995). One of the major developments, as discussed by Philip Reilly, was that of eugenics. Philip R. Reilly. THE SURGICAL SOLUTION 3 (1991). During the eugenics era, people who were deemed “feeble-minded” lost their rights through “custodial care” (institutionalization), and forced sterilization.

Social views of the “feeble-minded” could be seen in the 1927 *Buck v. Bell* case, where Justice Holmes, writing the opinion for the Supreme Court, stated that “three generations of imbeciles are enough.” In this case, the State Colony for Epileptics and the Feeble Minded claimed that the State of Virginia’s attempt to sterilize Carrie Buck (an institutionalized adult with mental retardation) “violated the Fourteenth Amendment by denying Ms. Buck due process of law and equal protection of the law.” HEALTH LAW 1138-40 (Barry R. Furrow et al., ed., 5<sup>th</sup> ed. 2001). The Supreme Court, however, cited the lower court’s finding that “Carrie Buck is the probable potential parent of socially inadequate offspring...” and continued by saying that it “is better for all the world if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, a society can prevent those who are manifestly unfit from continuing their kind.” *Buck v. Bell*, 274 U.S. 200, 207 (1927). Today, many involuntary sterilization laws still exist, although few are utilized. *Reilly* at 148.

<sup>75</sup> In the 1950s, institutions became the focal point for change. New trends in data began to indicate that many individuals with developmental disabilities had the ability to care for themselves if they were properly trained. Valerie Bradley. DEINSTITUTIONALIZATION OF DEVELOPMENTALLY DISABLED PERSONS 16 (1978). During the 1960s, reformers and civil rights promoters advocated for closure of mental hospitals and institutions developed during the eugenics era. Joseph Halpern et al. THE MYTHS OF DEINSTITUTIONALIZATION: POLICIES FOR THE MENTALLY DISABLED xiii (1980). Governmental reform began in 1962 with President Kennedy’s Panel on Mental Retardation, which confirmed the data and stated that mental retardation “can be prevented in some cases and ameliorated in most others.” Bradley at 5. By the mid-1960s, implementation of Medicare and Medicaid programs allowed for those with intellectual disabilities to receive medical and long-term care in the community. By 1965, the President’s Committee on Mental Retardation had been developed to assist with reform.

provision of health care to adults with M-BMR remain.<sup>76</sup> Such inequality persists in the realm of medical decision making as well. As we will see in Chapter 5, the current practice of medical decision making leaves a gap in providing equal opportunity for adults with M-BMR to understand the nature of their diagnosis, the treatment options, as well as the risks and benefits due to the lack of adequate supports. Part of this insufficiency might stem from the social stigma that adults with M-BMR still endure today,<sup>77</sup> part might be a result of the current health care

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In 1971, President Nixon announced a “national goal” of deinstitutionalizing one-third of those with mental retardation who were currently living in institutional settings. Bradley at 6. The objective was to provide supportive community living for these individuals through presidential directives, enforced by the Attorney General, and better housing options, to be developed by the Department of Housing and Urban Development. Three years later, President Ford re-affirmed this goal. *Id.* at 12.

In an effort to reduce discrimination and promote normalization, Congress passed the Rehabilitation Act of 1973. This Act prohibited federally funded programs from discriminating against disabled persons. Two years later, the Developmentally Disabled Assistance and Bill of Rights Act was enacted. Ann K. Wooster, Annotation, *Actions Brought Under Americans with Disabilities Act, 42 U.S.C.A. §§ 12101 et seq. -- Supreme Court Cases*, 173 A.L.R. Fed. 639 (2006).

The Act that had the greatest impact was the Americans with Disabilities Act, implemented in 1990. *Id.* It brought about elated responses in both houses including comments like that of Senator Tom Harkin who said, “It will change the way we live forever.” BACKLASH OF THE ADA (Linda Hamilton Krieger, ed., 2006).

The ADA expressly stated that segregation of individuals with disabilities was a form of discrimination. The ADA, and the cases that followed, sped up the process of deinstitutionalization.

The introduction of Supplemental Security Income (SSI) and supportive social services (through Title XX of the Social Security Act) helped to increase the ability of the disabled to assimilate into the community. As time passed, new standards such as those provided to intermediate care facilities through Medicaid sped up reforms. Bradley at 12.

<sup>76</sup> In 2001, the U.S. Surgeon General held a Conference on Health Disparities and Mental Retardation where he listened to the needs of the individuals and began to understand the inadequacies of the system. Following the conference, the Surgeon General noted “glaring deficiencies” in the provision of health care to both children and adults with mental retardation. He fervently requested that the public not only consider the findings, but *do something* about the problem. To *not* do so would “heighten the injustice this community [people with mental retardation] has too long endured,” he said. It’s time we heeded the call and consider the effects of the current health care system by attempting to improve one important part of that system: Health care decision making. See U.S. Public Health Service, *Closing the Gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation*, REPORT OF THE SURGEON GENERAL’S CONFERENCE ON HEALTH DISPARITIES AND MENTAL RETARDATION xi (2001).

<sup>77</sup> People with mental retardation are still often seen as a burden on society. The ethic of freeing the “disabled family” was observed in hospitals up through the 1980s, when obstetricians could be heard telling parents that they should immediately send their “mongoloid” child (a child with Down Syndrome) to an institution and forget the child was ever born. See Burke and McDaniel, *supra* note 39 at 31-32. Today, families that desire to care for their loved ones with M-BMR at home are left to fund most of that care privately. As health care costs rise, Medicaid, which is the source of many adults with M-BMR’s community care funding, has been a target for significant budget cuts. Group homes and assisted living facilities are available to some adults with M-BMR not living at home, but lack of funds for additional facilities leaves many on a long waiting list. In some states, funds for individuals with mental retardation are increasing, but at a much slower rate than the increase in need. Ann Belser, *Tight Funds Deny Services to State’s Mentally Disabled*, PITTSBURGH POST-GAZETTE, Jan. 29, 2007, A1-A2. See also Tom Koch, *The Difference that Difference Makes: Bioethics and The Challenge of “Disability.”* 29 JOURNAL OF MEDICINE AND

structure,<sup>78</sup> while another portion might be due to the lack of knowledge the medical community, and society as a whole, have about the decision making abilities of adults with M-BMR. The following section addresses this latter point to help those involved avoid arriving at potentially erroneous conclusions regarding the ability of adults with M-BMR to make informed medical decisions.

#### 4.1 RECENT PROGRESS IN UNDERSTANDING THE DECISION MAKING ABILITIES OF ADULTS WITH M-BMR

As will be discussed in Chapter 5, one of the underlying notions of informed consent is to promote the autonomous decision making power of the patient. In order to provide informed consent, the patient must have the capacity to understand the information that is being presented. Current medical practice does not leave much room for promoting the understanding of adult patients with M-BMR. Instead of allowing this practice to persist without question, Christine Cea and Celia Fisher provided empirical data to assuage assumptions that adults with M-BMR were unable to make competent informed decisions.

Using three standardized treatment vignettes and the MacArthur Assessment of Consent Capacity method,<sup>79</sup> Cea and Fisher questioned 90 study participants, some with mild to moderate

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PHILOSOPHY 697-716 (2004) (discussing two philosophical paradigms of personhood, one of which measures an individual's worth and personhood by their potential social and economic contribution).

Inadequate funding for adults with disabilities of any type can negatively influence the decisions that families are forced to make. For a discussion of one such decision, see *Ashley's Blog* at <http://ashleytreatment.spaces.live.com/>. See also Arthur Caplan, *Commentary: Is 'Peter Pan' Treatment Right?* at <http://www.msnbc.msn.com/id/16472931/> (updated Jan. 5, 2007) (In response to the family's decision, the director of the Center for Bioethics at the University of Pennsylvania, Arthur Caplan wrote "I...believe that a decent society should be able to provide appropriately sized wheelchairs and bathtubs and home-health assistance to families like this one").

<sup>78</sup> See *infra*, Chapter 6, Section 6.2 (b) (discussing the potential effects the current health care structure has on a physician's ability to provide adequate time and communication to an adult patient with M-BMR).

<sup>79</sup> The MacArthur Competency Assessment method requires a structured clinical interview aimed at assessing the patient's capacity to 1) understand the information, 2) appreciate that information, 3) reason and deliberate, and 4)

mental retardation, and others without mental retardation, as to their understanding and appreciation of the treatment vignette, what their medical decision would be, and their reasoning. The study found that, although adults with mild mental retardation found the choice and factual information to be more difficult than the participants without mental retardation, a majority of the adults were able to understand the information and decide (85% with mental retardation, as compared with 95% without mental retardation). With respect to appreciating the situation and consequences of the treatment, more than half of the participants with mild mental retardation (65%) were able to demonstrate full or partial appreciation, as compared with 85% of the participants without mental retardation. Over half of the participants with mild mental retardation (52%) were also able to weigh the benefits and the risks. Although these decisions were much more difficult for adults with moderate mental retardation, some participants were able to provide partial or full informed consent to each of the treatment vignettes.

There are many factors that could influence the ability of the individual to understand and appreciate information, to rationalize, and to communicate choices. Among those factors are experience and education. Children are not often able to rationalize their decisions without the training and guidance of parents and educators throughout their lives. If they were institutionalized, and their choices were always made for them, they might not develop the ability or the understanding of their rights to make such choices as adults. This could be one reason why adults with M-BMR are not as able to make medical decisions as those without mental retardation.

Regardless, what this study does indicate is that many adults with M-BMR are able to make informed medical decisions. Additionally, Cea and Fisher suggest that the research

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express a choice. *See* Thomas Grisso & Paul S. Appelbaum, *ASSESSING COMPETENCE TO CONSENT TO TREATMENT* 101-09 (1998). This method assesses the same basic capacities that are described by Buchanan and Brock. *See infra*, Chapter 5, Section 5.2.1.

indicates that the capacity of these individuals to consent “could be enhanced with supportive decision-making or educational techniques in preparation for treatments or procedures requiring their consent.”<sup>80</sup> Personal assistants would do just that.

#### 4.2 NEW UNDERSTANDING CALLS FOR NEW IDEAS

Although few studies have focused on the medical decision making capacity of adults with M-BMR, Cea and Fisher’s results indicate both a need for greater understanding of the topic as well as a change in the supportive decision making structure for adults with M-BMR. Chapter 7 will discuss the ways in which personal assistants could enhance the understanding that adults with M-BMR have about their diagnosis, treatment options, and the risks and benefits of such treatments. As Section 3.2.2 explained, completely autonomous medical decisions are unrealistic and should not be the goal. Rather, the goal should be to increase the patient’s understanding. Doing so would promote the patient’s autonomy to the greatest extent possible.<sup>81</sup> In the following chapter, we will see that this promotion of autonomy is a right of all patients, competent or not. Personal assistants would provide a means of promoting that autonomy of adults with M-BMR that is less restrictive than guardianship.

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<sup>80</sup> Cea & Fisher, *supra* note 7 at 84.

<sup>81</sup> Additionally, increasing the patient’s understanding would enable that patient to be more involved in the decision making process. Increasing patient involvement should be a goal of medicine to both promote that individual’s autonomy, but also to promote more positive outcomes, ultimately increasing the patient’s well-being.

## CHAPTER 5: THE LAW

### 5.1 HISTORY OF INFORMED CONSENT

The idea that medical decisions are to be made by the person to whom the treatment is to be administered has developed over time. Early history of medicine focused on a paternalistic approach<sup>82</sup> where the physician simply prescribed treatment with no opportunity for discussion.<sup>83</sup>

The first hints of patient rights to information about medical procedures emerged from tort claims against doctors. Such claims primarily arose from the principles of autonomy, human dignity, self-determination, and unwanted infringement of bodily integrity.<sup>84</sup> As stated in Chapter 2, personal autonomy is self-governance free from controlling influences of others and limitations, such as inadequate understanding, that prevent meaningful choice.<sup>85</sup> Violations were considered tortious acts of assault and battery, and a patient who endured such violations could

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<sup>82</sup> Buchanan & Brock, *supra* note 13 at 35.

<sup>83</sup> The role of the physician, in ancient Greece, was to instill patient confidence in his medical expertise. For this reason, patient involvement in decision-making was not considered. This sense of hope and comfort was seen in medieval medical writing as well. This view was seen through the Enlightenment stage and by many on through the nineteenth century.

<sup>84</sup> *Cruzan v. Harmon*. 760 S.W.2d 408, 416-17 (Mo. 1988) (Legal development of battery by physician, if procedure performed without appropriate consent, stemmed from the principle of autonomy). *See also Patricia E. Brophy v. New England Sinai Hospital, Inc.* 497 N.E.2d 626, 633 (Mass. 1986) (Referencing the common law notion of a person's right of individual autonomy over their own medical decisions, note 11 of *Brophy* opinion looks to philosopher, John Stuart Mill for insight. The court quotes John Stuart Mill, *On Liberty*: "The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or to forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise, or even right." John Stuart Mill, *On Liberty*, in 43 Great Books of the Western World 271 (R. Hutchins ed. 1952)). *See also* Alan Meisel & Kathy L. Cerminara, *THE RIGHT TO DIE* 2-21 to 2-27 (3<sup>rd</sup> ed. 2007) (discussing the principles upon which informed consent is based, in the context of the right to die).

<sup>85</sup> Beauchamp & Childress, *supra* note 25 at 58.

bring a civil malpractice suit against the physician.<sup>86</sup> The notion that a patient should at least be aware of the medical procedure that is about to be done to him was articulated as early as 1767.<sup>87</sup> Such ideology was seen in American courts beginning in the early twentieth century.<sup>88</sup>

In 1914, a more simplistic notion of consent was articulated by Justice Cardozo in *Schloendorff v. Society of New York Hospital*. In *Schloendorff*, Justice Cardozo stated that “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault, for which he is liable in damages... This is true, except in cases of emergency where the patient is unconscious, and where it is necessary to operate before consent can be obtained.”<sup>89</sup> This rule is now known as the doctrine of “simple consent” and has been expanded upon over time. It has influenced federal regulations of human clinical trials and has become a doctrine on which medical malpractice and criminal suits have been based. Informed consent forms for human experimentation, surgeries, and many other medical procedures have been developed to better document that patient consent has been obtained.

In the 1950s, case law began to indicate that physicians did not simply have a duty to obtain consent from their patients before providing treatment, but that they were also obligated to inform their patients of the known risks and benefits of the procedure, thus the doctrine of

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<sup>86</sup> Berg, *supra* note 56 at 41-42 (legal concern for bodily integrity is also seen in criminal law’s prohibition of battery (also homicide and mayhem)).

<sup>87</sup> Horthy, *supra* note 35 at Ch. 1, 1. (citing *Slater v. Baker*, 95 Eng. Rep. 860 (K.B. 1767) (upholding a verdict for the plaintiff, the court explained that performing surgery (“disunit[ing] the callous” from the patient’s leg in this case) without the patient’s consent is improper. The court believed that providing a patient with the knowledge of the surgery to be performed allowed him the ability to build his “courage.”)).

<sup>88</sup> See *Mohr v. Williams*, 104 N.W. 12 (Minn. 1905) (the court ruled that operating on both plaintiff’s ears when surgery for on the right had been consented to “amounted at least to a technical assault and battery.”). See also *Pratt v. Davis*, 79 N.E. 562 (Ill. 1906) (removing a woman’s uterus and ovaries without consent of the patient is a battery); *Rolater v. Strain*, 137 P. 96, 98 (Okla. 1913) (removal of an unusually placed bone in the patient’s foot, while draining the foot, when the patient expressly requested to retain all bones, was a “trespass upon her person” ).

<sup>89</sup> Cardozo cited *Pratt v. Davis*, 224 Ill. 300 (Ill. 1906); *Mohr v. Williams*, 95 Minn. 261 (Sup. Ct. Minn. 1905). Note that there are exceptions mentioned in this doctrine. Later cases have assisted in fleshing out further exceptions and additions as medical technology advances.

informed consent was born.<sup>90</sup> As medical technology advanced, the number of treatment alternatives increased, opening medical decision making up to greater ethical and legal discussion.

In 1972, two landmark cases shifted the focus of reasonable disclosure required for the patient to give informed consent from the point of view of the physician to that of the patient.<sup>91</sup> This shift reflected a trend toward greater autonomy of patients in medical decision making and, thus, self-determined treatment decisions.

Today, the doctrine of informed consent<sup>92</sup> has been considered to serve six main functions: It 1) protects individual autonomy, 2) protects the human dignity of the patient (one's "status as a human being"), 3) discourages fraud or duress, 4) encourages physicians to carefully contemplate their decisions, 5) promotes the patient's rational decision-making, and 6) involves the general public in medicine.<sup>93</sup> These functions all speak to the notion that each patient has inherent value and worth; her life is her own and her values are important. By informing the

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<sup>90</sup> See *Salgo v. Leland Stanford Jr. University Board of Trustees*, 317 P.2d 170 (Cal.App. 1957) ("A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment. Likewise the physician may not minimize the known dangers of a procedure or operation in order to induce his patient's consent." Here, the court held that the physician violated his duty to his patient (now paralyzed in the lower extremities after an aortographic examination) by neglecting to inform the patient of the details and possible risks of the procedure. See also *Natanson v. Kline*, 350 P.2d 1093 (Kan. 1960) (In this negligence case, the court held that the physician had a duty "to make a reasonable disclosure to the [patient] of the nature and probable consequences of the suggested or recommended...treatment, and he was also obligated to make a reasonable disclosure of the dangers within his knowledge which were incident to, or possible in, the treatment..."); *Mitchell v. Robinson*, 334 S.W.2d 11 (Mo. 1960).

<sup>91</sup> See *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972) (The court discussed the fact that "[t]rue consent to what happens to one's self is the informed exercise of a choice," and that in the medical field, where the average patient understands little about medicine, the doctor has the duty to provide "enough information to enable an intelligent choice", the scope of which is "measured by the patient's need."); *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972) (This court also said that the "scope of the physician's communications to the patient...must be measured by the patient's need, [or, in other words] whatever information is material to the decision").

<sup>92</sup> The doctrine of informed consent has influenced patient claims to various rights of refusing medical treatment as well as administration of treatment. These rights have not all been based in tort theory. For example, claims for the right to die (or to refuse life-sustaining medical treatment) have been based in the right of privacy, the right to equal protection of the law (Equal Protection clause of the 14<sup>th</sup> Amendment), and the right to due process (due process clause of the 14<sup>th</sup> Amendment). See U.S. CONST. amend. XIV, § 1.

<sup>93</sup> HEALTH LAW, *supra* note 24 at 356-57 (citing Alexander Capron, *Informed Consent in Catastrophic Disease Research and Treatment*. 123 U.PENN.L.REV. 340, 365-76 (1974)).

patient of the risks and benefits of medical treatments, as well as reasonable alternatives to the recommended treatment, the physician is acknowledging the patient as a human being with intrinsic dignity.<sup>94</sup> By obtaining the patient's consent to the treatment before administering such treatment, the physician is promoting that individual's autonomy, or self-determination.

In recent years, perhaps in response to medical malpractice suits requiring informed consent, legal and ethical discussions have further evolved to the point of defining the requisite capacity of a patient to consent to treatment. This decision making capacity is known as "competence" to make a medical decision, and will be discussed in detail in the following section.

## 5.2 THE CURRENT STATE OF DECISION MAKING FOR INCOMPETENTS<sup>95</sup>

### 5.2.1 ASSESSING ONE'S CAPACITY TO CONSENT

As a legal, ethical, and practical matter, capacity of an individual to make an informed medical decision is presumed for all adults.<sup>96</sup> This presumption may, however, be questioned and assessed by a physician if triggered by a particular event or circumstance during the decision making process.<sup>97</sup> Some examples of events or circumstances that would trigger an inquiry into the competency of the patient are the patient's demeanor, a change in mental state, inability or difficulty in communicating, or refusal of medical treatment to which most people would

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<sup>94</sup> See Cantor, *MEDICAL DECISIONS*, *supra* note 22 at 26-32.

<sup>95</sup> On page xxi of Buchanan & Brock, *supra* note 13, Buchanan and Brock state that "[a] very different...book could have been written on this same topic [(deciding for incompetents)], a book designed primarily to expose flaws and evils in our treatment of the incompetent and in the processes by which certain individuals come to be labeled "incompetent" in the first place, a book to stir the conscience, and to inspire and mobilize forces for social reform." They note that it would be a "worthy undertaking," but doubt that philosophers are the people to author it.

<sup>96</sup> Buchanan & Brock, *supra* note 13 at 216.

<sup>97</sup> Meisel & Cerminara, *supra* note 84 at 3-26.

consent. Even consent to treatment may trigger an inquiry into a patient's competency if, for example, the patient consents to an exceptionally risky or invasive procedure.<sup>98</sup>

Allen Buchanan and Dan Brock explained, in the oft-cited and widely utilized book that details medical decision making for “incompetents,” entitled Deciding for Others, “[a] competence determination...is a determination of a particular person’s capacity to perform a particular decision-making task at a particular time and under specified conditions.”<sup>99</sup> What this means is that competence is “decision-relative.”<sup>100</sup> The nature of the decision and the “conditions under which [that decision] is to made” are determinative factors when evaluating a patient’s competence to make that decision.<sup>101</sup> What is common to both parts is that the physician (or judge in cases where judicial evaluation of the evidence, including physician’s professional opinion, is required to determine competence) analyzes the nature and conditions of the understanding as they relate to the patient.<sup>102</sup> Although there is no single definition of incompetence that is accepted today,<sup>103</sup> Buchanan and Brock offer a general approach to determining competence in medical decision making that has been more or less adopted by the medical community. Their approach states that in order for a patient to exhibit competence in

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<sup>98</sup> Grisso & Appelbaum, *supra* note 79 at 61-76. See also Meisel & Cerminara, *supra* note 84 at 3-26.

<sup>99</sup> Buchanan & Brock, *supra* note 13 at 18.

<sup>100</sup> *Id.*

<sup>101</sup> *Id.*

<sup>102</sup> An important issue to note here is that, unless a third party (e.g. Psychiatrist, neurologist, or judge) is present, or is provided evidence, to analyze both the nature of the disclosure (i.e. That adequate disclosure of relevant diagnoses, treatments, risks, and benefits was provided in a way that a reasonable patient would understand) and the competency of the patient (i.e. The patient’s ability to understand, communicate that understanding, to reason and deliberate, and to utilize her own set of values in making a decision), there is no check on the physician’s provision of information to the patient. Essentially, competency evaluated only by the physician is ambiguous and subjective. Providing a personal assistant, as is offered in the coming chapters, is a way to avoid some of this ambiguity and subjectivity in instances where a personal assistant is required. The parameters laid out (as well as parameters that should be discussed by hospital administrators), in the coming chapters, for when a personal assistant is necessary should provide fairly descript guidelines that would ease the subjectiveness of determining when such a personal assistant is necessary.

<sup>103</sup> Meisel & Cerminara, *supra* note 84 at 3-18 (citing U.S. Dep’t of HEW, *Protection of Human Subjects – Research Involving Those Institutionalized as Mentally Infirm: Report and Recommendations of the Nat’l Comm’n for the Protection of Human Subjects of Biomedical and Behavioral Research*, 43 Fed. Reg. 11,328, 11,345-46 (1978) (“Court definitions of competency... vary.”)).

making the medical decision, four general capacities are required<sup>104</sup> of the patient: 1) understanding of the diagnosis, its effects, possible treatments, and subsequent side effects and outcomes of the treatments;<sup>105</sup> 2) communication of that understanding; 3) ability to reason and deliberate (which utilizes the two former capacities); and 4) a set of values, or conception of what is good.<sup>106</sup>

Legally or philosophically, competence is task-oriented. A person may be deemed competent to pick out the type of fruit he or she would like to eat, but may not be competent to solve a chemistry problem even after being taught the basic concepts. Similarly, a patient who is visiting her primary care doctor for a regular check-up and is asked whether she would like an antihistamine prescribed to her might be competent to make such a decision, but incompetent to decide whether or not to undergo chemotherapy for advanced cancer.

As illustrated in the above examples, the types of medical decisions that must be made can range from fairly simple decisions that have minimal impact on the patient's life to life-limiting or life-prolonging effects that have serious, possibly deadly, impact on the patient and lives of the patient's family. The affective state of the person in each of the examples can range from peaceful, centered, and organized to paranoid, anxious, depressed, and chaotic.<sup>107</sup>

Additionally, the patient's intellectual functioning, as determined by IQ tests and functional capacity formulations, could range from fully functioning to profoundly mentally disabled. For many individuals with profound mental retardation, the question of decision making competence, based on the nature and conditions under which that decision is to be made, never arises. Due in

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<sup>104</sup> Buchanan and Brock identified these four capacities as three, combining the first two, but I have separated "understanding" and "communication" to enhance the reader's understanding of competence.

<sup>105</sup> Buchanan & Brock, *supra* note 13 at 23-25. *See also* Meisel & Cerminara, *supra* note 84 at 3-20.

<sup>106</sup> Buchanan & Brock, *supra* note 13 at 23-25. *See also* Grisso & Appelbaum, *supra* note 79 at 101-109.

<sup>107</sup> As stated earlier in this section, a patient's demeanor or mental status can trigger a competency evaluation. The patient's demeanor or mental status may be linked to the affective state of the patient. However, this thesis focuses more on the potential that the patient's intellectual functioning and or treatment refusal has triggered the evaluation.

part to society's lack of knowledge about the mental functioning of those with intellectual disabilities, and in part to lack of knowledge about potential educational and translational supports that could enhance such individuals' decision making abilities, many adults M-BMR are deemed incompetent to make their own medical decisions and, thus, a legal guardian is often required to make decisions for the individual.<sup>108</sup>

### 5.2.2 THE PROCESS OF ASSIGNING A SURROGATE DECISION MAKER

In health care, the idea that a surrogate should be appointed to make a decision for a person deemed incompetent to make her own decisions was seen in the landmark case, *In re Quinlan*.<sup>109</sup> One of the rulings that the court made in that case was that a competent person who is now in a permanently unconscious state has a legally protected interest in accepting or declining life-sustaining treatment and that, to give effect to that that interest, a guardian must be allowed to decide for the patient in a way that the patient would have decided if she were competent (i.e., the substituted judgment standard).<sup>110</sup> Several courts have extended that right to incompetent individuals who never held the capacity to consent.<sup>111</sup>

If a patient is deemed incompetent to make the medical decision at hand, the question then becomes who the surrogate decision maker should be and whether that surrogate decision maker must be designated through judicial proceedings or may be assigned in the clinical setting.<sup>112</sup> If dealing with a formerly competent individual, often the assessment of competence for the medical decision at hand is determined in the clinical setting and a surrogate decision

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<sup>108</sup> Please note that if delay in treatment might impact the medical condition or survival of the patient, emergency procedures should be followed. Also, verification of legal guardianship "should never delay the provision of needed care." Harty, *supra* note 35 at 12.

<sup>109</sup> *In re Quinlan*, 355 A.2d 647, 670 (N.J. 1976).

<sup>110</sup> *Id.*

<sup>111</sup> See *Saikewicz*, 370 N.E.2d 417 (Mass. 1976). See also *Foody v. Manchester Memorial Hosp.* 482 A.2d 713, 718 (Conn. Super. 1984); *John F. Kennedy Memorial Hospital v. Bludworth*, 452 So.2d 921, 921 (Fla. 1984).

<sup>112</sup> Meisel & Cerminara, *supra* note 84 at 3-11.

maker, if deemed necessary, is chosen in the clinical setting as well.<sup>113</sup> Ideally, adults with M-BMR, in the clinical setting, are treated in the same manner as formerly competent individuals.<sup>114</sup> If this method is chosen, then the physician may look to the family member who is present to make the medical decision.<sup>115</sup> This method might be seen more regularly in outpatient settings when the physician is offering non-invasive or minimally invasive procedures that are medically indicated to produce great benefit and little risk.<sup>116</sup>

With increased concern about privacy violations under HIPAA,<sup>117</sup> and the ever-present concern of malpractice suits alleging lack of informed consent,<sup>118</sup> what is more commonly seen in clinical practice is erring on the side of placing adults with M-BMR in, what scholars have labeled, the “never-competent” category.<sup>119</sup> This could be because of prior assessments made by the physician,<sup>120</sup> an inappropriate assumption that mental retardation is the equivalent of decision making incompetence,<sup>121</sup> or the assumption may be legally required because of a prior adjudication of the individual’s full incompetence, or incompetence as to medical decision

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<sup>113</sup> See *Id.* at 3-12 (discussing surrogate decision making for end-of-life issues).

<sup>114</sup> See *e.g.*, *Saikewicz*, 370 N.E.2d 417, 423 (Mass. 1977).

<sup>115</sup> This method has been statutorily provided for in some states. See ARIZ. REV. STAT. § 36-3231 (2006); MISS. CODE ANN. § 41-41-211 (2007).

<sup>116</sup> I have observed outpatient check-ups with adults with Down Syndrome where the physician has asked the parent whether or not they would like their young adult to have a ten year pneumovax shot. Medical evidence indicates that adults with Down Syndrome are more prone to upper respiratory infections and complications related to pneumonia than the general population. Thus, the vaccine appears to weigh on the side of great benefit with minimal risk.

<sup>117</sup> See Bryan K. Touchet et al., *The Impact of Fear of HIPAA Violation on Patient Care*, 55 PSYCHIATRIC SERVICES 575-76 (2004).

<sup>118</sup> See *supra*, Chapter 5, Section 5.1.

<sup>119</sup> Cantor, *MEDICAL DECISIONS*, *supra* note 22 at 35-39. See generally Cantor, *Bane*, *supra* note 22; Eric C. Miller, *Note: Listening to the Disabled: End-of-Life Medical Decision Making and the Never Competent*, 74 Fordham L. Rev. 2889 (April, 2006).

<sup>120</sup> As was noted earlier, general assessments of an individual to make *all* medical decisions should not be the accepted norm. It should be the last resort of medical practitioners in the category of determining competency for medical decision making since competency is task or decision-specific. See Buchanan & Brock, *supra* note 15 at 18.

<sup>121</sup> Although this assumption is sometimes made, the physician who makes it must recognize it as discriminatory. Each individual with mental retardation is as different as each person without mental retardation. Not only is it an inappropriate assumption, but it is also an illegal one. See FLA. STAT. § 765.204 (2007); 53 D.C. Reg. 7940 (d)-(d)(2) (Among other things, (d) incapacity to make health care decisions was not to be “inferred from the fact that an individual: (2) Has mental retardation or has been determined by a court to be incompetent to refuse commitment under Chapter 13 of Title 7).

making, and subsequent appointment of a guardian<sup>122</sup> for the person, or limited guardian for the purposes of making medical decisions. Even in cases where the adult with M-BMR has not been

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<sup>122</sup> As history shows, decisions for individuals with intellectual disabilities were often made by others; at times the parents, at other times medical advisory boards of the institution where the individual lived, and at still others it was the state. Very little was left up to the individual. In some cases, as we saw was the case regarding involuntary sterilization, state laws were enacted to allow others to make decisions for the “feeble-minded.” The most common method for others to make decisions for individuals with developmental disabilities is guardianship. Guardianship is a legal relationship granted by a court that creates both a right and duty for a person (“petitioner” at trial; “guardian” after the trial, if granted) to care and decide for a minor or a person deemed incapacitated (referred to as “ward” after the guardianship has been granted). The role of a guardian has changed over time.

Before the 18<sup>th</sup> century, English law provided guardianships to keep the public safe from the “insane.” Sarah Pope. *Young Adults with Cognitive Impairments: A New Reason for Greater Utilization of Limited Guardianship*, 2007 (unpublished paper, University of Pittsburgh) (on file with author). At that time, guardianship also served as a mechanism to keep the “insane” person’s estate safe for his or her heirs. The doctrine that allowed for the King (and later the state) to establish such guardianships became known as the *parens patriae* doctrine. This doctrine focused on the public welfare and the safety of the family’s wealth, but it neglected the well-being and best interests of the person it was established for: The individual with a developmental disability.

Similarly, the United States adopted the *parens patriae* doctrine to grant the states power to protect those who were unable to protect themselves. Perhaps due in part to the eugenics perspective, the focus did not shift from protection of others to the protection of the individuals with developmental disabilities until the late 1960s and early 1970s.

As we have seen, in the context of deinstitutionalization, the 1960s civil rights movement brought change in social perspective. In 1969, Title V of the Uniform Probate Code (UPC) was enacted by the National Conference of Commissioners on Uniform State Laws. *Id.* Title V provided a definition of an “incapacitated person”, to clear up confusion and reduce inappropriate labeling, and created court-appointed investigators to uncover the true necessity of each guardianship petitioned for. Scholars urged further reforms in the form of limited guardianships, but it wasn’t until the Associated Press (AP) published a series on guardianship abuses<sup>122</sup> that Congress heeded the call.

The aim of limited guardianship is to provide the necessary safety and protection for those individuals needing guardianship while also promoting their autonomy and self-determination to the greatest extent that guardianship is able to. *Id.* Although limited guardianships could decrease the extent of potential harm imposed on the ward, and could increase the ward’s autonomy, evidence shows that it is still under-utilized today.

Currently, only a minority of parents or caregivers apply for any form of guardianship of their child or client. This has many health implications for the person with intellectual disabilities, as we will see in the coming chapters.

Guardianship, be it full or limited, restricts the individual’s autonomous decision making power. It also leaves the individual in a vulnerable position. If a guardian is granted power over the person’s estate, abuse of the ward’s finances are possible and have been seen in many instances.<sup>122</sup> In the health care context, abuses may be (and have been) observed when a health care decision is made for the ward, by the guardian, that focuses on interests other than that of the ward. One timely example may be seen in what is now called the “Ashley treatment.” At the age of six, Ashley’s parents (who are the legal guardians until she turns eighteen) consented to surgical procedures that would cause her to remain at her current size for the rest of her life. The surgeries involved were a hysterectomy (to prevent menstruation), removal of her breast buds (to prevent breast development), and an appendectomy. In addition, Ashley was placed on estrogen therapy in order to stunt her growth. Ashley’s parents explained that these treatments would enable them to transport Ashley more easily and *might* reduce the risk of sexual molestation by caregivers. *See Ashley’s Blog at* <http://ashleytreatment.spaces.live.com/>. Although Ashley’s parents attempted to cast such drastic and invasive procedures in the shape of Ashley’s best interests, it seems clear that the interests of the parents are being promoted by performing these procedures. In a recent interview, Director of the Center for Bioethics at the University of Pennsylvania, Arthur Caplan, stated that “[k]eeping Ashley small is a pharmacological solution for a social failure – the fact that American society does not do what it should to help severely disabled children and their families.”

considered never-competent, but simply incompetent to provide informed consent for a particular medical procedure, the physician, medical team, or hospital administration might request a guardian be judicially appointed to provide the requisite informed consent before providing treatment.<sup>123</sup>

If the patient has been deemed never competent, or if the hospital, physician, or medical team requests that a guardian be appointed for an individual with mental retardation in order to obtain informed consent for treatment, a petition for guardianship of the person may be filed with the court. The petitioner must submit medical testimony and other evidence providing that the potential ward (i.e., the individual that the petitioner is seeking guardianship over) is indeed incompetent. In some states the evidence must be clear and convincing.<sup>124</sup> The individual herself must be present unless a physician testifies that there is a potential the individual's presence would cause mental or physical harm to the individual.<sup>125</sup> The burden of proving such harm is high, and therefore many adults with mild to moderate mental retardation are present to hear their loved one or caregiver state to a judge that they are "incompetent." For most adults with mental retardation, often the bases for their being deemed incompetent are mental age and

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The following chapters aim to address the social inequities that adults with intellectual disabilities face as they relate to medical decision making. The program suggested aims to offer a more comprehensive solution to the problem than guardianship or limited guardianship currently provide.

<sup>123</sup> See Joseph Shapiro, *All Things Considered: Dispute Over Mental Competency Blocks Transplant*, NATIONAL PUBLIC RADIO, December 22, 2006 at <http://www.npr.org/templates/story/story.php?storyId=6665577> (Story of a twenty-five year old female, named Misty, with mild mental retardation who was deemed incompetent to provide informed consent for a kidney transplant that could save her life. The health care facility refused to place Misty on a transplant list, but offered that her potential for a future placement on the list may rest in whether or not she is appointed a guardian to decide on her behalf.).

<sup>124</sup> See e.g., 20 PA. CONS. STAT. ANN § 5511 ("The court, upon petition and hearing and upon the presentation of *clear and convincing* evidence, may find a person...incapacitated..."). See also 21 D.C. CODE § 21-2204 (2007) (requiring "*clear* evidence that the person is incapable of understanding the health-care choice"). But see 17-A N.Y. SURR. CT. PROC. ACT § 1750-A (2007) (requiring only that a person be deemed "developmentally disabled" in order to authorize the court to appoint a guardian).

<sup>125</sup> See 20 PA. CONS. STAT. ANN § 5511 ("The alleged incapacitated person shall be present at the hearing unless... the deposition or testimony of the physician or licensed psychologist states that "his physical or mental condition would be harmed by his presence...").

functional capacity, which by definition would most likely have been even less developed in earlier years, thus placing them in the “never competent” category.

Assuming the parent or caregiver, having petitioned, has been granted full legal guardianship of the person, the physician is often then required to accept the guardian’s decision.<sup>126</sup> A legal guardian must make decisions using any evidence of the incompetent’s wishes prior to her becoming incompetent,<sup>127</sup> but if it was determined that the individual being discussed was never competent, this requirement would not apply.<sup>128</sup>

When there is no express wish, guardians must then attempt to decide for the individual in the way they believe the individual would decide if she were competent (the “likely choice” the now incompetent would make).<sup>129</sup> This standard, known as substituted judgment, is a subjective standard based on the values and preferences of the individual. Some states have held this principle to apply to never competent individuals.<sup>130</sup> This application to never competent individuals, however, has been questioned by various scholars including Norman Cantor.<sup>131</sup> In his book entitled *MAKING MEDICAL DECISIONS FOR THE PROFOUNDLY MENTALLY DISABLED*, Cantor cites a Massachusetts Supreme Court decision that “admitted that substituted judgment is ‘a legal fiction’ as applied to a never competent person...”<sup>132</sup> Cantor explained that, in

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<sup>126</sup> See ARIZ. REV. STAT. § 36-3231 (2006) (“[I]f the court appoints a guardian for the express purpose of making health care treatment decisions, that guardian shall act as the patient’s surrogate.”); UTAH CODE ANN. § 75-5-312 (2) (2006) (“Absent a specific limitation...the guardian has the same powers, rights, and duties...that a parent has respecting the parent’s unemancipated minor child...”). See also PA Department of Public Welfare, PROCEDURES FOR SUBSTITUTE HEALTH CARE DECISION MAKING, Nov. 30, 1998 (“It is expected that health care providers will...respect the decisions of substitute decision makers appointed ...”).

<sup>127</sup> Norman Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J.L. Med. & Ethics 182, 190 (2001) (referring to surrogate guidance on end-of-life decision making).

<sup>128</sup> But see Miller, *supra* note 122 at 2889 (discussing the importance of listening to the express wishes of the individual, especially where it involves physical resistance, non-cooperation with treatment, pulling tubes, and verbal expressions of refusal).

<sup>129</sup> Cantor, *Twenty-Five Years After Quinlan*, *supra* note 130 at 190 (citing *Saikewicz*, 370 N.E.2d 417, 423 (Mass. 1977)); *Bludworth*, 452 So.2d 921 (Fla. 1984); *In re Colyer*, 660 P.2d 738 (Wash. 1983).

<sup>130</sup> See, e.g., *Saikewicz*, 370 N.E.2d 417, 423 (Mass. 1977).

<sup>131</sup> Cantor, *MEDICAL DECISIONS*, *supra* note 22 at 41-42.

<sup>132</sup> *Id.* at 42 (citing *In re Jane Doe*, 583 N.E.2d 1263, 1267-68 (Mass 1992)).

*Saikewicz*, the court stated it applied the substituted judgment standard, but it was a best interests standard shrouded with the cloak of a “substituted judgment” label.<sup>133</sup> Cantor’s reasoning is that a person cannot truly claim to be using substituted judgment if the individual has never shown any evidence of expressing her own wishes related to the topic at hand.

If we assume that the expressions made must be those of a competent person at one time, it would appear that Cantor is correct in his analysis. In *Saikewicz*, the probate court determined that refusing treatment would be in the best interests of Mr. Saikewicz, a 67 year old with profound mental retardation. In holding that Saikewicz’s privacy interest and right to self-determination outweighed any State interest in protecting Mr. Saikewicz from his own decision, the Supreme Judicial Court of Massachusetts noted that the negative effects of chemotherapy weighed heavily against the notion that most people elect for treatment and desire a longer life. This part of the decision applied the best interests standard. Unlike the probate court, however, the Supreme Judicial Court of Massachusetts claimed that the substituted judgment standard could be employed in reaching the final decision that Saikewicz would not want to be treated if he were competent. The court stated that “Saikewicz’s inability to cooperate with the treatment” (due to his lack of understanding of the treatment side effects), were particular to Mr. Saikewicz and, thus indicated that Saikewicz’s desire would be to refuse treatment if in fact he was competent.<sup>134</sup> Since the court does not appear to have misinterpreted the meaning of competence (i.e., Mr. Saikewicz’s lack of understanding did indicate his incompetence to make the particular medical decision), it seems the court must have assumed that Mr. Saikewicz’s fear (created by his lack of understanding) would remain even if he were to understand the reasons for and side effects of treatment (i.e., if he were competent). This assumption, however, seems to be

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<sup>133</sup> *Id.*

<sup>134</sup> *Saikewicz*, 370 N.E.2d 417, 432 (Mass. 1977).

inappropriate without further discussion of Mr. Saikewicz's values, aims, and preferences, or proof that he had once expressed a meaningful refusal of the treatment. There is no such discussion in this case. It seems that the only possible factor indicating what Mr. Saikewicz would have decided if he were competent was Mr. Saikewicz's mental impairment labeled as a "lack of understanding." This alone could not indicate what Mr. Saikewicz's wishes would be if he did understand. Therefore, the standard must have been a best interests standard.

In cases where a patient's express wishes, or likely wishes cannot be determined, a decision that is deemed in the best interests of the patient must be made.<sup>135</sup> Unlike the substituted judgment standard, the best interests standard is an objective test with the goal of promoting the patient's well-being.<sup>136</sup> Such a standard, while altruistic in nature, is also the most autonomy-restrictive. With this in mind, some commentators have recommended that this principle be further loosened as regards guardians who are close blood relatives of the individual ("bonded guardians").<sup>137</sup> One commentator, bioethicist Robert Veatch, explains that loosening the best interests standard for bonded guardians would allow for the bonded family members' values, emotions, and needs to be considered. Such values, emotions and needs should be considered, he argues, because family members are deeply connected to the individual, and are also the most appropriate people to be making such decisions: Thus, judgment of their decisions should be tempered. Norman Cantor also recommends that, when the guardian is a parent, the choice made should not have to be the best choice, "so long as it is a plausible medical option and is not so antithetical to the patient's interests as to constitute neglect or abuse."<sup>138</sup>

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<sup>135</sup> Cantor, *Twenty-Five Years After Quinlan*, *supra* note 129 at 191.

<sup>136</sup> *Id.*

<sup>137</sup> Veatch, *supra* note 17 at 441-42 (recommending that bonded guardians be preferred over non-bonded guardians).

<sup>138</sup> Cantor, *Bane*, *supra* note 22.

While allowing bonded guardians greater discretion in medical decision making for their incompetent relatives (or “loosening” the best interests standard, as Veatch proposes) might be a worthy consideration in certain contexts, such as terminally ill patients who are at the end of life and are permanently unconscious, applying this idea to all adults with M-BMR remains inadvisable. Allowing any person discretion to decide for the patient with M-BMR in a way that does not tend to promote the patient’s best interests or autonomy is to allow a health care treatment to be administered, or denied, using interests other than those of the patient. As stated earlier, in some contexts, such as those where the patient’s culture or religion would require respect for the guardian’s autonomy and interests over the patient’s (assuming the patient had freely accepted that culture),<sup>139</sup> or where the patient is terminally ill and permanently unconscious, loosening the best interests standard for a familial bonded guardian decision might be acceptable. However, even in those rare instances where loosening the best interests standard is considered, the physician would be required to strictly scrutinize the guardian’s reasoning. If there is any doubt in the physician’s mind, judicial resolution is recommended.

As explained in Chapter 3, this does not mean that the bonded guardian’s interests would not be considered. Family or non-familial bonded guardian interests would be discussed in collaborative decision making approach.<sup>140</sup>

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<sup>139</sup> As Beauchamp and Childress illustrate, this type of example still promotes the patient’s own autonomy since the patient has *chosen* to be a part of that culture or religion. However, since people’s values and choices are not static, it could be said that any present autonomy that the patient might currently possess is not furthered by allowing the bonded guardian to decide against the best interests of the patient. A discussion of present autonomy is outside the scope of this thesis.

<sup>140</sup> See *supra*, Chapter 3, Section 3.2, *Collaborative Decision Making*.

### 5.2.3: THE LEAST RESTRICTIVE ALTERNATIVE: A GOOD APPROACH

Guardianship is currently the only certain way to ensure that an adult with any degree of mental retardation receives the care he needs when he needs it, or is not denied access to a potential treatment, such as being placed on an organ transplant list.<sup>141</sup> As we have seen, guardianship does not allow for the most self-determined, independent medical decision making of adults with M-BMR.<sup>142</sup> Beginning in the late 1980s, guardianship procedures were reformed to provide the individual in need of assistance with support that least restricts that individual's autonomy.<sup>143</sup> In accordance with the reforms, legislatures across the country began requiring the courts to institute the "least restrictive means"<sup>144</sup> of guardianship, with a preference toward limited guardianship.<sup>145</sup>

Although limited guardianship orders have increased over the years,<sup>146</sup> and a few courts have allowed various support services to suffice in place of limited guardianship for adults with

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<sup>141</sup> See, e.g., Shapiro, *supra* note 123.

<sup>142</sup> Additionally, limited monitoring of guardianship leaves the system and the individual open to abuse. Such abuse was uncovered by the Associated Press (AP) in 1987 and led many states to reform guardianship statutes in such a way that would limit the potential harms to the ward. It has been suggested that increased guardianship monitoring would require additional funds. In this proposal, the topic of funding has not been addressed. If guardianships are not properly monitored just because funds are lacking, a comparison of funds required for both this proposal and funds required for guardianship monitoring would be required. However, guardianship still tends to restrict the patient's autonomy to a greater extent than providing personal assistants would. For a discussion about lax guardianship monitoring, see Sarah Pope, *Young Adults with Cognitive Impairments: A New Reason for Greater Utilization of Limited Guardianship*, 2007 (unpublished paper, University of Pittsburgh) (on file with author).

<sup>143</sup> See Jennifer L. Wright. *Protecting Who from What, and Why, and How? A Proposal for an Integrative Approach to Adult Protective Proceedings*, 12 Elder L.J. 53, 60 (2004). See also Sally Balch Hurme. *Current Trends in Guardianship Reform*, 7 Md. J. Contemp. L. Issues 143, 145 (1995/1996).

<sup>144</sup> 20 PA. CONS. STAT. ANN. §5502 (2006) states that "every individual has unique needs and differing abilities" and, thus, this chapter is dedicated to promoting the "welfare of all citizens by establishing a system which permits incapacitated persons to participate as fully as possible in all decisions which affect them." The statute also states that it is dedicated to "meeting the essential requirements for [the incapacitated person's] physical health and safety, protecting their rights, managing their financial resources and developing or regaining their abilities to the maximum extent possible;" to meet these objectives, Section 5502 establishes a system "through the use of the least restrictive alternative."

<sup>145</sup> See FLA. STAT. § 744.344 (2007) ("must be the least restrictive appropriate alternative"); N.Y. MENTAL HYG. § 81.21 (2007) ("least restrictive form of intervention"); 2006 KY. REV. STAT. ANN. 387.500(3) ("partial guardianship...shall be the preferred form of protection and assistance for a disabled person"); 20 PA. CONS. STAT. § 5512.1 (2006) ("The court shall prefer limited guardianship."). See also Hurme, *supra* note 148 at 145 (lists other states up to 1996 that have a preference for the least restrictive alternative).

<sup>146</sup> See Wright, *supra* 148 at 60. See also Hurme, *supra* note 148 at 145.

mental retardation,<sup>147</sup> such practices are infrequent. Recent statistical analyses of guardianship cases have shown that even in states that implemented reforms decades ago, there is only very minimal preference toward limited guardianship.<sup>148</sup> One member of the Probate and Trust Council of the Allegheny County Bar Association who is well-versed in estate planning and guardianship proceedings, Steven Seel, opined that administration of limited guardianship seems to be “impossible.”<sup>149</sup> He explained that judges do not have the time or ability to determine “how limited” a guardianship should be.<sup>150</sup> Special Master for the Allegheny County Orphan’s Court, Paul Steffano, explained that his understanding was that limited guardianships require “more detailed information and specific testimony from doctors and witnesses.”<sup>151</sup> Mr. Steffano’s opinion was that the detailed information required for limited guardianship orders was burdensome to obtain, rendering plenary guardianships preferable. Although one may question

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<sup>147</sup> In Pennsylvania, not only does the Guardianship Reform Act require the court to prefer limited guardianship, but it also requires the court to “make specific findings of fact” as to the “need for guardianship services, if any, in light of such factors as the availability of family, friends and other supports to assist the individual in making decisions...” 20 PA. CONS. STAT. ANN. §5510, et seq. (2006). This means that even if the petitioner proves that the potential ward is incapacitated for purposes of guardianship, if the potential ward is able to show that she has sufficient supports to render guardianship unnecessary, then those supports, being less restrictive than guardianship, shall be preferred. This meaning played out in *In re Peery*, where a sixty year old woman with cognitive impairments, who required supports to maintain her “health, welfare, safety, and medical needs”, was deemed to have sufficient supports in the form of family and friends to render guardianship unnecessary.

Although *In re Peery* represents one of the first cases of its time, its presence indicates that courts are open to promoting the underlying goal of the reforms that are still being codified in states today. That goal is to provide support to individuals with intellectual disabilities in the least restrictive way possible, thus promoting their autonomy with a mindfulness toward their well-being. *In re Peery*. 727 A.2d 539 (Pa. 1999).

<sup>148</sup> A study cited by the American Bar Association’s (ABA) Commission on Law and Aging reported that, as of 2006, Colorado judges were more likely to use limited orders than those in Massachusetts or Pennsylvania, but use of limited guardianship was still fairly low there (In Colorado, 34% of guardianships were limited whereas in Massachusetts, only 1.3% of guardianships were limited and in Pennsylvania only 2.7% of guardianships were limited). In Allegheny County, Pennsylvania, the 1992 Guardianship Reform Act of Pennsylvania calls for the court to “prefer limited guardianship,” but only six of the two hundred fifty four guardianships that were appointed in 2005 were limited guardianships. That is lower than the state average for limited guardianship use (2.4% in Allegheny County versus 2.7% statewide average).

<sup>149</sup> Telephone Interview with Steven Seel, Parter, Thorp Reed & Armstrong (June 30, 2006).

<sup>150</sup> Additionally, Steven Seel suggested that court funds do not allow for the extensive reviews that he thought would be necessary, nor did they have the resources to hear the multiple return petitions that were sure to be requested when the ward was deemed further incapacitated. Funding is a topic of discussion for this proposal as well.

<sup>151</sup> Telephone Interview with Paul Steffano, Special Master, Allegheny County Orphan’s Court (July, 2006).

the validity of such observations, the practical result has been that limited guardianships are rarely utilized.

### 5.3 A NEED FOR CHANGE

One of the main functions of the doctrine of informed consent is to promote the autonomy of the patient.<sup>152</sup> This ideology has been extended to all patients, including those who are deemed incompetent to make their own decisions.<sup>153</sup> Although guardianship is a form of surrogate decision making that attempts to further the interests of incompetent patients, unless a limited form of guardianship is employed, it does not allow for competency assessments to be decision-relative. Rather, it allows for a sweeping assessment of incompetency. This severely restricts the autonomous decision making power of many adults with M-BMR who may be able to make many informed decisions and leaves them open to abuse. Although legislative requirements to prefer limited guardianship attempted to address this concern, and promote the autonomy of such individuals, it has yet to be widely used. Since limited guardianship is not utilized,<sup>154</sup> it is time to consider other practical alternatives that are less restrictive than guardianship. One such alternative would be to introduce personal assistants to the medical decision making process for adults with M-BMR.

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<sup>152</sup> Part of the underlying notion of informed consent is that the patient should have the right to decide, and is often in the best position to know, what will enhance her own well-being.

<sup>153</sup> See *supra*, Section 5.2.2, *The Process of Assigning a Surrogate Decision Maker* (discussing *Saikewicz*, 370 N.E.2d 417 (Mass. 1977)).

<sup>154</sup> See Sarah Pope, *Young Adults with Cognitive Impairments: A New Reason for Greater Utilization of Limited Guardianship*, 2007 (unpublished paper, University of Pittsburgh) (on file with author) (discussing a 2006 American Bar Association study that revealed that, even in states that had passed reforms two decades ago, limited guardianship was rarely preferred – one such state was Pennsylvania where, in 2006, only 2.7% of guardianships were limited).

## CHAPTER 6: ETHICAL IMPLICATIONS

### 6.1 THE RESULT OF CURRENT PRACTICES: EXCLUSION OF ADULTS WITH M-BMR FROM THEIR OWN MEDICAL DECISIONS

As we have seen, many adults with M-BMR are trapped in a health care system that does not have adequate alternative support mechanisms to enhance what autonomous decision making ability they do have. Currently, the system either allows for (a) a determination in the clinical setting that the individual is competent to make her own medical decision, (b) a determination in the clinical setting that the individual is incompetent to make her own medical decision and a surrogate decision maker (most often the parent or caregiver who is present)<sup>155</sup> is chosen at the time the decision needs to be made, or (c) a clinical determination that the individual is incompetent to make her own medical decision and, if it is not an emergency,<sup>156</sup> judicial guardianship appointment is requested. Regardless of which path is followed, the potential for harm, discrimination, abuse, and mere disrespect for the individual's own human dignity exists. Recognizing that competency is decision-relative, equalizing the opportunity for adults with M-BMR to understand those decisions may require additional supports. Allowing the procedures of the current system to continue without providing additional supports (i.e., personal assistants)

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<sup>155</sup> This reality was confirmed in an interview with Dr. Peter Bulova, a primary care physician for the Adult Down Syndrome Clinic, located at the University of Pittsburgh Medical Center (UPMC), Montefiore, Pittsburgh, PA.

<sup>156</sup> In cases of emergencies, an emergency guardianship is often requested, but certain emergent circumstances render a guardian impractical and unnecessary.

indicates that we have not yet stepped outside the bounds of discrimination toward individuals with cognitive impairments.

## 6.2 REALITY: AN ETHICAL DILEMMA

As stated, the current system of health care decision making for adults with M-BMR is inadequate to protect their autonomy and dignity, and fails to respect the fact that, although their intellectual functioning may not be what we consider “normal,” they may still possess some ability to participate in making their own medical decisions. This is illustrated through observation of the practical problems the system produces and the ethical dilemmas that arise. To gain a better understanding of the practical and ethical problems, we must look at each potential method of decision making:

(a) The physician does not question the competence of the patient:

Current ethical theory and law favor a medical system where competency is presumed.<sup>157</sup> In medical practice, this presumption allows for greater expediency in providing medical care to patients. It also favors the autonomy of the patient. The incident that most often triggers a competency evaluation occurs when a patient refuses a recommended treatment.<sup>158</sup> For adults with mild to moderate mental retardation, this concern may not arise in many cases where the adult truly does not understand the nature and consequences of her consent, but consents anyway. To illustrate, we return to Mr. Doe.

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<sup>157</sup> See *supra*, Chapter 5, Section 5.2.1, *Assessing One’s Capacity to Consent*.

<sup>158</sup> Interview, Peter Bulova, Primary Care Physician, UPMC, in Pittsburgh, PA (Mar. 15, 2007).

In John Doe's case, let us assume that the physician requesting a diagnostic stress test did not want to provide that test unless Mr. Doe consented on his own.<sup>159</sup> Perhaps because of lack of time, or a belief that the stress test was a recommended diagnostic test for a man with Mr. Doe's symptoms, in the end, the physician accepted Mr. Doe's consent. However, when the stress test was performed, it was apparent that Mr. Doe had not fully understood what was going to happen. His response, and subsequent years of anxiety prior to and following doctor's visits indicate that the presumption of competence negatively affected Mr. Doe's well-being.<sup>160</sup>

With respect to well-being, providing a surrogate decision maker of any sort in this instance would not have solved the problem. Having a surrogate decide that the stress test was in the best interests of Mr. Doe would only have allowed for less discussion with Mr. Doe and potentially even less understanding on his part. What might have helped was to have someone there, someone he was familiar with, to support him during his time of confusion – to assure him that this would help him.<sup>161</sup>

However, providing support and comfort to Mr. Doe in order to help him comply with the treatment may raise the question of coercion. Let us assume that the person offering to support Mr. Doe is the supervisor of the group home. The supervisor, having worked many years in close contact with Mr. Doe, has developed a particular relationship with Mr. Doe. This relationship is not one where both Mr. Doe and the supervisor stand on equal footing, but one where Mr. Doe understands that the supervisor may exercise authority over him at the group home. Although the supervisor may sweetly offer Mr. Doe support through the diagnostic test,

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<sup>159</sup> See *supra*, Chapter 1, Section 1.2, *Just a Simple Stress Test*.

<sup>160</sup> See *supra*, Chapter 2, *Independence and Personhood: An American Tradition*, for a discussion of how well-being plays into the goals of the medical profession.

<sup>161</sup> Evidence of the value of this type of support played out in Mr. Doe's case when, a future visit when Mr. Doe agreed to have the same procedure done, knowing what it was, when the manager of his group home offered to hold his hand through the procedure and be there for him during the entire test.

this offer may be recognized by Mr. Doe as the supervisor's way of exerting power over him. Perhaps Mr. Doe has been asked to clean his room at times, with the same sweet offer of support, but when he refused he was reprimanded in some way. If the supervisor was aware that Mr. Doe recognized her tone as that of the "clean your room" request, and meant it in a way that exerted authority, it could be considered coercive. However, it could be difficult for the physician to recognize this without considerable discussion, or paying close attention to body language. Although this by no means represents most cases, it is one covert form of potentially coercive influence.

Support offered by a group home supervisor, employee, or even a family member with whom the patient with M-BMR lives seems to have a lower threshold for being considered coercion anyway. Many adults with M-BMR have additional health care needs that they have relied on others to help with throughout their lives. Just as a physician holds a large amount of authority in the decision making process due to the patient's vulnerable state and lack of medical knowledge, the family member or group home employee whom the patient has relied upon holds a great deal of authority in the patient's daily life. This is important to recognize in the medical decision making context, and may be valid a reason to introduce a personal assistant into the process. The patient with M-BMR might not feel as vulnerable with someone there who tells her that what she thinks and feels is valuable and whom she does not see as a medical authority or a caregiver she desires to please.

Of course, not all adults with M-BMR feel dominated or controlled by their caregivers or family. Many adults with M-BMR feel more comfortable with their family or caregivers than with anyone else. Often, these are the people that the adults with M-BMR truly confide in. However, since this relationship is potentially imbalanced, and since the personal assistant is not

to fill a role of the ultimate decision maker, it is advisable to provide the personal assistant for visits involving adults with M-BMR. Doing so would provide greater balance to every visit, even if only a minority of visits are significantly imbalanced.

To assume that anyone makes decisions absent any influences at all is foolhardy. As was discussed in Chapter 3, patient medical decisions are always influenced by information and recommendations the doctor provides, and are often influenced by external considerations, such as a family member's feelings, personal or family economic burden, religious and cultural influences, just to name a few. I will call these "natural influences." The differences between natural influences and coercive influences are not clear cut, since any influence could potentially become coercive, or reduce the patient's autonomous decision making power if considered to be determinative in the patient's life. As was discussed in Chapter 3, coercion is "[the use of] force to gain compliance,"<sup>162</sup> or, at its best, is "improper influence that deprives a person of freedom of choice or substitutes another's choice or desire for the person's own."<sup>163</sup> Natural influences, in most cases, are influences that play a role in the patient's decision, but do not create a feeling of forced compulsion.

While personal assistants could aid in reducing the potential coerciveness of support in cases where a treatment is medically recommended and the patient consents after being offered support, these are not typically cases where the coerciveness of support is, or should be questioned. Indeed, they are rarely questioned in similar cases involving patients without mental retardation. In these cases, obtaining consent of the patient involved a discussion with that patient and the treatment was considered in the best interests of the patient. The cases that raise the more concern are those in which medical treatments or refusals are not medically

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<sup>162</sup> Dictionary.com. *Coercion*, Lexico Publishing Group, at <http://dictionary.reference.com/browse/coercion> (2007).

<sup>163</sup> *Id.*

recommended, are diagnostic in nature, or have a number of reasonable alternatives to choose from.<sup>164</sup> In these cases, especially the cases where treatments are not medically recommended, the coerciveness of support is not the only factor that may be detrimental to the patient's well-being; the decision to undergo treatment may result in negative health consequences for the patient.

For example, consider Sally, who was discussed in note 41, with a few different circumstances. Sally is 28 years old with what seems to be healthy sexuality. She often masturbates in bed, which creates quite a mess for the caretakers at the group home to clean up during her periods. Unlike the example discussed in note 41, however, Sally was offered a few different forms of birth control by the physician. Among them were the pill, an intra-uterine device (IUD), condoms, and Depo-Provera. Sally, who has not become sexually active with anyone (and has no intent to), refuses all of the birth control methods. The physician accepts her refusal. After Sally leaves, the caregiver who had accompanied her to the visit makes it a point to inform Sally, each time she gets in trouble with the staff for messing the bed during periods, that if she received the Depo shot she would not get in trouble as much. At Sally's next visit, the physician asks Sally if she would like to consent to any of the birth control methods. The caregiver urges Sally to consent to the Depo treatments and offers to drive her to the visits each month. Though still sexually inactive with other people, Sally agrees. Some possible side effects of Depo shots are pain, decreased sexual desire, fatigue, depression, and darkening of the skin on the upper lip, under eyes, and on the forehead (called chloasma). Since Sally was not sexually active, and had no intent to be at that time, the only benefits she might experience are shortened and less frequent periods. The side effects could possibly harm Sally's well-being and

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<sup>164</sup> Obtaining consent to research that does not directly benefit the patient is probably the most questionable, but discussion of this topic has been considered by numerous ethicists and is outside the scope of this discussion.

the fact that she submitted to, rather than freely choosing, the treatment could definitely impact her emotional well-being.

As with instances where coercion might have been present, but the treatment was medically recommended, the covert coercion in cases where the treatment is not necessarily indicated might only be discovered through considered discussion.<sup>165</sup> A personal assistant in these cases could open the lines of communication, ask questions that might indicate whose values and interests are being furthered, and could advocate for Sally if interests of the caregiver and Sally appear to be in conflict. Not only would the personal assistant be providing support to Sally, but he would also be providing support to the physician in helping her to understand when coercion is involved and initiate discussion about the fact that her role as a physician is to provide medical treatment to the patient that benefits the patient, not the caregivers. Using the personal assistant, this type of discussion could remain in the physician's office rather than a courtroom.

A few other issues that are raised both by the physician allowing Mr. Doe to go home and “think about” consenting to another diagnostic stress test and by the physician asking Sally whether or not she would like to consent to birth control at both visits are related to the patient's return home to further evaluate the decision. The fact that there is no way for the physician to know what goes on the drive home, or at home, raises two questions: 1.) How valid is a consent that is provided by a patient with M-BMR who leaves the office to “think about it” and returns a few weeks later, and 2.) How is coercive decision making determined?

Neither of the questions have a clear answer nor does the fact that there is no clear answer indicate that allowing a patient with M-BMR to go home and think about a decision

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<sup>165</sup> It is important to note that coercion, although undesirable, is not something that is completely avoided in medical visits involving patients without mental retardation. Therefore, coercion should be avoided when possible, but should not necessarily determine whether or not the patient is able to make her own decision.

should not be allowed. There are circumstances where any patient, regardless of mental functioning, requires more time to consider to a treatment offered, such as a case where the patient has just received information that she has cancer and is asked whether or not she would like to undergo chemotherapy treatments. Indeed, a physician might question the competence of a patient who automatically consents to chemotherapy without any time to allow the reality of the situation set in.<sup>166</sup>

In situations where consent is normally obtained at the same visit and in situations where the patient is allowed to go home to think, a personal assistant could prove helpful. First, in situations where the medical treatment is fairly routine and consent is obtained at the visit, the personal assistant could help the physician to explain the diagnosis, treatment, risks and alternatives in a way that is meaningful to the patient with M-BMR. Second, the personal assistant could offer support that has significantly less potential of being coercive than the support offered by the family member or caregiver. Third, in situations where the patient decides to return with an answer, coercion may not be observable, but the personal assistant could foster a collaborative discussion between the patient, physician, and caregiver to increase the understanding of whose values and interests are involved and how to come to a decision. Essentially, the personal assistant would serve as a mediator in the effort to minimize or eliminate the necessity of judicial proceedings and to reduce the potential that a decision is made by the patient as a result of coercion.

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<sup>166</sup> In situations like Mr. Doe's the need to ensure Mr. Doe's full understanding seems even more imperative. The caregiver who was present at the visit, and whose competence was not evaluated since he or she is not being looked at to make a decision, may not have fully understood the physician's explanation of the treatment options, or necessity of a diagnostic test, but may feel an obligation to help Mr. Doe come to a decision. Due to the caregiver's lack of understanding, Mr. Doe may come to a decision using erroneous information. The supervisor or community living specialist, perhaps feeling an obligation to persuade Mr. Doe that such a test is necessary (although that understanding might be erroneous), may explain the procedure inaccurately, or minimize the risks of the treatment. At the next appointment, the patient decides in favor of the test even though he is not fully competent. The result could be a loss of human dignity and a potential reduction in well-being due to the coercion and misunderstanding involved.

(b) The physician deems the patient incompetent to make her own medical decision and looks to the attending caretaker as the surrogate decision maker.

As explained earlier, surrogate decision making provides a means of respecting an incompetent patient's autonomy by allowing another to decide in a way that the patient would have decided if he or she were competent. In health care visits where an adult with M-BMR is the patient, many practical and ethical issues arise.

First, as was seen earlier, the question of competence arises more frequently in cases where an adult with M-BMR is the decision maker, resulting from valid concerns about the patient's ability to understand and appreciate the nature of the diagnosis, the treatment options, or the risks and benefits of such treatments. Where an adult with M-BMR is involved, there are many other potential factors that weigh in. For example, a physician who has little experience working with individuals who have decreased cognitive abilities might be unaware, or self-conscious about the most effective ways to present medical information to the patient. This possibility, combined with time constraints, leaves little room for continued attempts on the part of the physician. In these instances, the physician might automatically defer to the attending caregiver for consent. To illustrate, let's turn to Bill's check-up with the family care physician.

Bill is a 30 year old man with mild mental retardation. Bill is a big talker at the home and has no problems expressing his preferences. However, he is shy around strangers. When Bill enters the doctor's office, the physician greets him and he responds with a mumbled, "Hey." Bill's mother has accompanied him to the visit. She is a shy woman who was brought up during the more paternalistic days of medicine and thus does not think that explanation of Bill's

different demeanor is of relevance to the physician. During the visit, the physician receives very minimal responses from Bill when she questions him directly. Knowing that Bill has mild mental retardation, the physician begins to discuss Bill's health status with his mother, frequently making eye contact with Bill, but with more limited direct discussion. At the end of the visit, the physician turns to the mother and mentions that because of Bill's condition, he is at higher risk for pneumonia. She asks Bill's mother if she would like for Bill to be immunized that day and explains that the shot would be good for ten years. Although Bill is still sitting there, acknowledgment of his presence has diminished to a point that even eye contact is infrequent. The mother consents and the two are hustled out of the office to the lab where a nurse will administer the injection.

In Bill's case, it appears that the physician made a covert competency evaluation during the visit. The physician's decision to request consent from Bill's mother was probably influenced by a number of factors. Among them may have been a desire to avoid upsetting Bill by questioning his mother directly about his abilities in front of him, an assumption that Bill's IQ or lack of response indicated an inability to understand the information about the immunization that she was about to present, or a desire to respect the needs and concerns of the mother who had spent so many years caring for her son.

Although the decision to immunize Bill may have been in his best interests, and his mother may have decided in a way that Bill would have at home, the physician's covert competency assessment left Bill out of the conversation about the immunization and out of the ultimate decision. These facts indicate that the goals of informed consent have not been met and Bill's potential autonomy had not been respected. Therefore, informal, covert competency

assessments like this should not be made.<sup>167</sup> Additionally, it cannot automatically be assumed that Bill's autonomy is being promoted by deferring to a surrogate decision maker.

In Bill's case, even if the physician had properly determined that Bill was incompetent to consent to the immunization and had looked to his mother as the surrogate decision maker, certain practical and ethical problems could arise.

First, although the doctrine of informed consent requires that adequate information be provided to the competent patient to make an informed decision, in cases involving incompetent patients the only person the physician must provide adequate information to is the surrogate decision maker. As we have seen in Bill's case, this often means that the incompetent patient himself is not communicated with by the physician. This is often the case with patients with M-BMR who might be competent to consent if provided with a bit more attention, compassion, and communication. Time being a valuable commodity in health care, both financially and in the sense of a physician's desire to assist as many people as he can, patients with M-BMR are often ignored (and surrogates are consulted) at times where expediency is desired by the physician.<sup>168</sup>

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<sup>167</sup> Sweeping assessments may be appropriate in the medical context, but only if another physician is consulted, or a psychiatrist is asked to perform a competency examination. The MacArthur test for assessing competency calls for a clinical interview, or a structured assessment tool, coupled with a mental status evaluation. By this stage, the clinical interview has already been performed by the physician in an attempt to obtain informed consent from the patient. Therefore, when the psychiatrist arrives, much of her focus is on the mental status of the patient. For adults with M-BMR, IQ is usually a determining factor. This is the practical reality for adults with M-BMR which is addressed within this thesis.

<sup>168</sup> Among other reasons a physician may not communicate with a patient who has been deemed incompetent is the lack of financial support offered by the current health care scheme. Currently, physicians cannot bill for time. Physicians are reimbursed for each patient they see, how many body systems they cover (the various ailments the patient is experiencing), and how in-depth the treatments are (the more procedures necessary, the more to bill for). Due to these circumstances, attempting to assist a patient with M-BMR in understanding the procedure that needs to be consented to is not a financial priority (This reality was discussed in an interview with Peter Bulova, Primary Care Physician at UPMC, in Pittsburgh, PA on March 15, 2007). Changing the current health care structure to follow more of a physical complexity of the patient scheme might be one way to promote greater discussion with adults with M-BMR. Personal assistants might also help in expediting the process in some cases. However, it cannot be assumed that implementing a personal assistant program would reduce health care costs. While allowing monetary gain to drive actions, especially in health care, might be considered quite unethical, it is a reality in our society and in medicine that we cannot ignore. Both the discussion of altering the current health care financing scheme and of funding a personal assistant program are necessary, they are outside the scope of this thesis.

From an ethical standpoint, when a physician looks to a person other than the patient with M-BMR (who is sitting in front of her) for consent to treatment, that patient's potential autonomy is not respected. In essence, the patient was not afforded a full competency evaluation and was stripped of his right to make his own medical decision. Denying a patient with M-BMR the right to make his own medical decision without valid reason (i.e., a proper determination of incompetency), violates our fundamental notions of freedom<sup>169</sup> and the goals of informed consent.<sup>170</sup>

When the patient has been afforded the full competency evaluation, and has been deemed incompetent, refraining from further communicating with the patient, at least about the procedures, disrespects that patient's intrinsic human dignity. All patients deserve the respect of acknowledgement of their presence and importance, at the very least. To defer to a surrogate decision maker does not violate this respect, but ceasing to address or acknowledge the patient with M-BMR, who is sitting right in front of the physician, does.

As has been explained, a personal assistant could further the legal and ethical goals of medicine by promoting equal opportunity to understanding the information provided for adults with M-BMR and by serving as a communication liaison between the patient and doctor. The personal assistant could accompany the nurse or medical assistant who performs the initial physical assessment, thus increasing the physician's knowledge of the patient before entering the examination room. During the visit, the personal assistant could provide physicians with the tools to communicate more effectively and directly with the patient by rephrasing complex explanations, paying close attention to the unique educational needs of the patient, and easing the

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<sup>169</sup> See *Saikewicz*, 370 N.E.2d 417 (Mass. 1976) (incompetents have the same right to decide as competents); *In re Peery*, 727 A.2d 539 (Pa. 1999) (supports that least restrict the autonomy of the individual with mental retardation are to be preferred).

<sup>170</sup> See *supra*, Chapter 2, *Independence and Personhood*; Chapter 5, Section 5.1, *History of Informed Consent*.

tension that the physician may feel when working with such individuals is a fairly new experience. Additionally, the personal assistant would ensure that the patient is communicated with even in instances where the patient may be deemed incompetent. This inspires respect for the autonomy or, at the very least, the inherent human dignity of each patient with M-BMR.

Second, as a practical matter, a surrogate decision is quite ineffective when it does not involve willing participation of the patient. For example, if Bill were to squirm or throw a temper tantrum, or was unwilling to sit still for the needle stick, he would not be a very good candidate for the immunization. In an ethical sense, if restraints must be applied, one must question the emotional effects upon Bill's well-being and the disempowerment or indignity he might experience in weighing the beneficial nature of the immunization. The effects and ethical nature of applying restraints are heightened depending upon the invasiveness and necessity of the procedure as well. In Mr. Doe's case, the potential benefits (is it life-saving, life-sustaining, improving the quality of the individual's life, and should extending life or increasing quality of life be important?),<sup>171</sup> must be weighed against the length of the procedure, the physical effects upon his body (does it involve minimal risk? Is it a painful or scary procedure?), and the emotional trauma that Mr. Doe might experience as a result (will applying restraints risk traumatizing this individual, thus reducing his quality of life or his well-being?).<sup>172</sup>

Often the recommended treatment is considered desirable by the reasonable person. This is probably true for adults with M-BMR as well. With this in mind, it would be quite appropriate to consider ways in which the potential risks to the patient's well-being could be reduced. As

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<sup>171</sup> A stress test indicates whether a person's heart function is normal, mildly abnormal, moderately abnormal, or severely abnormal. There is only about a three percent increase in heart-related health events in adults with severely abnormal heart functioning versus those with normal heart function. See Peter Bulova, *Non-Invasive Cardiac Testing* (2004) (on file with author).

<sup>172</sup> Additionally, it is commonly known that stress may affect a person's risk of heart attack. A test that causes stress for Mr. Doe not just initially, but has impacted his level of stress when visiting the doctor for years following the test, must be critically analyzed before performing it without the actual consent of the patient.

with any patient, patients with M-BMR will often feel more at ease when their concerns and needs are addressed by the physician. Additionally, the support of someone they are familiar with could reduce their stress. In Mr. Doe's case, it is quite possible that his tension, and subsequent trauma, could have been greatly reduced if someone had taken the time to ask him about his concerns with the procedure and really listen. A personal assistant would be well-versed in the listening technique, would acknowledge his concerns through repetition so that he could feel empowered and so that the physician and caregiver could better understand his concerns, and would help to ease his tensions by explaining the procedures in a precise yet less threatening manner. Finally, in a case like Mr. Doe's, the personal assistant could accompany the patient with M-BMR to the procedure, address any questions or concerns he may have during the procedure, and hold his hand, if desired. This type of communication and physical support can be very helpful in situations where the patient may not exactly know what to expect.

(c) The physician deems the patient incompetent to make her own medical decision and, provided it is not an emergency,<sup>173</sup> requests that a legal guardian be appointed to make the decision.

Cases like this are known to occur where the decision involves use of a scarce resource and continued self-care is required following the procedure. For example, consider Misty, a 25 year old female with mild mental retardation, who was born with abnormally small kidneys. Recently, Misty was evaluated by a transplant team at Oklahoma University Medical Center who

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<sup>173</sup> In cases of emergencies, an emergency guardianship is often requested, but certain emergent circumstances render a guardian impractical and unnecessary.

later deemed her incompetent to consent to the transplant and, thus denied placement on the transplant list.<sup>174</sup>

The transplant team stated that she might be eligible for placement on the transplant list if legal guardianship was sought and the guardian was willing to consent to the treatment. This assertion was made even though Misty's primary care physician and her physician for dialysis (two physicians unassociated with the hospital offering the transplant procedure) claimed that she was competent to consent to a transplant procedure.

To Misty, this came as a surprise and a severe blow to her own self image and hope for a full life. Misty was a person who was very independent in her daily life. She worked, enjoyed bowling, was involved in a committed relationship, and was keenly aware that she was sick. She lived at a group home which allowed her freedom to make choices, but also provided her with a supportive environment in which to thrive.

Misty had been undergoing dialysis for a long time. She had consented to that treatment herself and her visits were pleasant because she understood that the treatments, though painful, were to help her get better. She also knew that without a kidney transplant she would soon die.

So what was the reason the hospital committee deemed Misty incompetent and in need of a guardian? Mary Ellen Albrish, a clinical psychologist at the Virginia Commonwealth University Medical Center explained that part of the reason might lie with the transplant team's seemingly moral obligation to determine who will be a successful patient. The transplant team might believe Misty's cognitive disability could render her unable to follow the rigorous and expensive drug regimen following treatment to ensure that her body accepts the transplant.

It is difficult to believe that the transplant team members would base their entire decision on a patient's intellectual ability, but it appears that might have been the case here. Misty had

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<sup>174</sup> Shapiro, *supra* note 123.

been deemed competent to make other difficult medical decisions by two other physicians, such as consenting to kidney dialysis. Her track record with it appeared to be flawless as well. Misty was able to prepare herself for work and to be ready in time for her transportation. She also had the ability to know what type of person she desired to be in a relationship with. And, most importantly, Misty had the support and assistance of the group home staff to ensure that she would follow the rigorous drug regimen following surgery.

If the transplant team truly did decide based on Misty's intellectual abilities alone, it appears they did not consider their ethical and legal obligations of providing a non-discriminatory means of determining transplant eligibility. For a health care team to ever assume that there are not supports available to an individual such as Misty, without a thorough investigation, is an incompetent practice in itself. Steven Reese, an expert on developmental disabilities at Ohio State University, believes that discrimination based on intellectual ability is a factor in denying adults with mental retardation such transplants. "There's thinking out there that some people's lives are more valuable than others," Mr. Reese states. To refute any misconceived belief that individuals with mental retardation would have decreased survival rates in comparison to the general population, Mr. Reese recently published a study that demonstrated quite the opposite: Of the 42 known cases in which individuals with mental retardation received kidney transplants, 100% were still surviving one year after the transplant, and 90% were still surviving after three years. Mr. Reese believes that much of this could be a result of the increased support that these individuals receive in a group home such as Misty's.

Although the external circumstances might have indicated that Misty was able to handle the surgery, it is important to understand that competence evaluations are decision-relative. With this in mind, there is a potential that the transplant team truly felt that Misty was incompetent to

consent to this extremely invasive procedure. Although dialysis is a fairly invasive procedure, it does not compare to a major transplant surgery. A high level of understanding and appreciation for the nature of the procedure, the risks and benefits, and the alternatives is required. In Misty's case, she may have understood the risks and the benefits, but perhaps she was unable to communicate that understanding to the transplant team. This would be an ideal place for a personal assistant to provide his or her services. In a way, the caseworker already was providing this service, but the difference is that if the caseworker speaks for Misty, the transplant team does not see it as Misty's values or preferences. It could also have been the way in which the caseworker spoke for Misty. For example, if someone from the transplant team asked Misty if she could explain her understanding of the risks, if Misty didn't answer right away (whether out of nervousness, or some other emotion) the caseworker might have responded with, "She's a bit nervous now, but she told me that the risks meant..." the transplant team might see this as either (a) the caseworker's own feelings or understanding, or (b) a patient who is being coerced into consenting to the transplant. Translating for a patient is not seen as a part of a caseworker's professional duties and caseworkers are not trained for such roles.

Personal assistants, on the other hand, would be trained in assisting the patient to express her own thoughts, feelings, and values. They would understand the ethical nature of ensuring that medical decisions are made by the patient and would recognize the potential coerciveness of certain language and support. Also, since translating and interpreting unique communication skills would be a part of their professional duties, the personal assistants' opinions and recollections would be more accepted as a part of the informed consent process for the transplant team. It is, however, very important to note that personal assistants should *not* be the ultimate communicators of a decision. Their role is to assist the patient in communicating the decision

herself. If the personal assistant has exhausted all resources and is still unable to produce understanding for the patient, it would be the personal assistant's duty to inform the physician or transplant team and allow them to discuss the option of guardianship limited to the transplant decision. This, however, should be the method of last resort.

Not only could providing a personal assistant in cases such as Misty's support adults with M-BMR in making more autonomous decisions, but it could expedite the process so that the adults are able to get on transplant lists, or receive treatment, sooner. This is extremely important to people like Misty whose life is dependent upon receiving the transplant.

## CHAPTER 7: APPLYING THE PROPOSAL

Having illustrated the reasons for, and importance of, involving a personal assistant in health care visits for adults with M-BMR, we now must understand practical side of implementation. How will a personal assistant program, coupled with a collaborative decision making approach work?<sup>175</sup>

### 7.1 IMPLEMENTATION OF THE PERSONAL ASSISTANT PROGRAM

As a consultant without financial ties to the health care facility or to the family or caregivers, the personal assistant would have the ability to maintain a particular caseload, and could follow the adults with M-BMR in that caseload to each of their various health care visits. Inevitably, some of the scheduled visits within that caseload will conflict. Thus, creation of a personal assistant “team” would be essential. At least two members of the team would become familiar with a specific patient in the caseload. That way, if one member is unable to attend the visit, another familiar member could fill in.

Although the role of the personal assistant has already been explained, let us look at it within the context of collaborative decision making. Chapter 3, Section 3.2 explained that medical decision making affects and involves a number of different people, their experience,

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<sup>175</sup> It is important to recognize that the proposal offered in this thesis is a theoretical concept and has yet to be introduced to an actual clinical setting. With this in mind, the following recommendations can be considered with an eye toward improvement and alteration.

knowledge, values, preferences, and interests. Underlying the physician's professional duty are a number of moral principles including the respect for the patient's autonomy, the promotion of the patient's well-being, the principle of non-maleficence (to do no harm), and the principle of justice.

Although the historic approach of medical decision making was paternalistic in nature, a more patient-determined approach prevails today. However, patient decision making has never been completely self-determined.<sup>176</sup> The learned physician, having years of medical study and experience under her belt, holds the medical knowledge and the ability to apply that medical knowledge to the particular circumstances of the patient. The patient, on the other hand, holds the most important values, preferences, and interests to apply during the decision making process. In terms of medical decision making involving adults with M-BMR, there are often family members or caregivers whose values and interests are uniquely tied to the adult with M-BMR and whose intimate understanding of the patient lend to the discussion. For this reason, ethical discussion has moved toward a collaborative (or shared) decision making approach.<sup>177</sup>

The personal assistant, being well-versed in ethics, is keenly aware of the values and interests that are involved in the decision making process and also understands the authority that the physician holds over the decision making process. While the personal assistant serves as the advocate of the patient with M-BMR, the most vulnerable and important person in the decision making process, she also encourages discussion that uncovers the various values and interests

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<sup>176</sup> Jay Katz discusses this notion in *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984). See also *supra*, Chapter 3.

<sup>177</sup> See Timothy Quill & Howard Brody, *Physician Recommendation and Patient Autonomy: Finding a Balance Between Physician Power and Patient Choice*, 125 *ANNALS INT. MED.* 763-69 (1996). See also Glyn Elwyn et. al. *Shared Decision Making and the Concept of Equipose: The Competences of Involving Patients in Health Care Choices*, 50 *BRIT. J. GEN. PRACT.* 892-97 (2000); Michael J. Barry, *Health Decision Aids to Facilitate Shared Decision Making in Office Practice*. 136 *ANNALS INT. MED.* 127-35 (2002); Simon N. Whitney, *A New Model of Medical Decisions: Exploring the Limits of Shared Decision Making*, 23 *MED. DEC. MAKING* 275-80 (2003); Ronald Epstein et al., *Communicating Evidence For Participatory Decision Making*, 291 *JAMA* 2359-66 (2004).

that are present. Additionally, the personal assistant helps the physician in disseminating the medical information and the physician's professional opinion and recommendations, thus transferring authority to the patient with M-BMR. With increased authority, the patient begins to feel more empowered and more able to make an informed decision. Once the patient has made a decision, that decision is discussed, and if consensus has not been reached, the following procedures should be followed:

Because the patient with M-BMR is the person most affected by the medical decision, there should be a strong presumption in favor of the patient's preference, and underlying values and interests. If, however, it appears that the patient's preference might have been coerced, the personal assistant or the physician (if the physician is not the one coercing the patient) should address this. If resolving the issue in-house appears to be impossible, judicial guidance may be necessary.

If the patient's preference is not coerced, and the patient expresses a competent and informed decision, the patient's decision should be honored. If, however, the patient is not able to express her understanding even through the use of the personal assistant, the physician should identify a surrogate decision maker for that particular decision. Unlike current surrogate decision making procedures, the presence of a personal assistant promotes continued conversation between the patient and physician regardless of the involvement of a surrogate decision maker. Additionally, the personal assistant will become a familiar face to the patient and, thus will be able to provide support to the patient if the surrogate must override the patient's decision.

In cases where the medical decision is quite complex or invasive, and a surrogate decision maker is necessary, application for guardianship limited only to the decisions for the

procedure is advisable. However, the personal assistant should remain an integral part of the procedure and a source of support for the patient.

In all cases, the most appropriate method of gaining informed consent is from the patient herself. If the patient requires a “translator,” the personal assistant could serve as this, but would follow guidelines similar to that of a language translator.<sup>178</sup> If a surrogate decision maker is necessary, informed consent should be obtained directly from him or her.

It is, however, important to note that if a patient with M-BMR requests that the family member, caregiver, or physician make the decision for that patient, this does not mean that the patient has become less autonomous.<sup>179</sup> As with a patient whose culture calls for another person to make their medical decisions, if the patient with M-BMR expresses understanding and an underlying reason for the choice, and that choice is fairly rational once expressed fully (with the use of the personal assistant, if necessary),<sup>180</sup> then that choice should be honored as well. The act of choosing another decision maker, in itself, may also be considered an autonomous choice.<sup>181</sup>

## 7.2 PRINCIPLES THAT COULD GUIDE THE COLLABORATIVE APPROACH

As with placing different amounts of importance on different involved parties’ values and interests in the decision making process, the collaborative decision making process itself is more useful in particular contexts. In an article aimed at “exploring the limits of shared decision making,” Simon Whitney proposes certain types of decisions that should be made by the

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<sup>178</sup> The fact that the personal assistant is merely a translator should limit her liability, but discussion of this topic should be sought before implementing such a program.

<sup>179</sup> Beauchamp & Childress, *supra* note 25 at 62.

<sup>180</sup> It is important to note that fully rational decisions are not often required of patients without mental retardation. Therefore, although rationality is desirable, it should not (in all cases) determine the decision making capability of the adult with M-BMR.

<sup>181</sup> *Id.* (“promoting one’s autonomy” does not place a *duty* on them to choose, but provides them with the *right* to choose. “Even if the patient delegates that right to someone else, the choice to delegate is itself autonomous.”).

physician, others that should be made by the patient, and a number of decisions that should be made collectively.<sup>182</sup> Although Whitney does not acknowledge the importance of family involvement in the decision making process, his conclusions provide direction for future medical decision making policy.

In *A New Model of Medical Decisions: Exploring the Limits of Shared Decision Making*, Whitney divides medical decisions into various levels of importance as well as certainty.<sup>183</sup> He states that decisions of low importance (those that have a low impact on the health and well-being, or those that do not significantly impact the moral, financial, social, legal, or aesthetic being of the patient) and high certainty (decisions that have “a widely accepted clinical response” and few reasonable alternatives) should be made by the physician. An example of such a decision would be whether or not to add “oblique views” to an X-ray of the finger. Whitney observes that most patients would not feel a great need to decide such issues and would not have the expertise to understand the importance. Thus, the physician should decide. At the other end of the spectrum, decisions that have high importance (those that have a high impact on the health and well-being of the patient) and low certainty as to the results that treatment might provide should be decided by the patient. The example Whitney provides is of the choice between “mastectomy and lumpectomy with radiation for localized breast cancer.” The results for either are very unclear while the impact on the patient is immense.

The zone of collaborative decision making, as I call it here, would be the large range of decisions in which the certainty and the importance are the vast middle between these two extremes. In these cases, the diagnosis, possible treatments, and risks and benefits should be carefully explained by the physician. The physician should explore the patients’ values and

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<sup>182</sup> Whitney, *supra* note 177 at 275-80.

<sup>183</sup> *Id.* at 276-77.

understanding, as well as the considerations that the accompanying caregiver provides.<sup>184</sup> The personal assistant should help in this exploration with further questions, if need be.

Whitney also mentions one zone of decision making that may raise potential conflict between the patient and physician, a zone where consensus may not be obtainable. This is the zone of decisions that are of major importance and high certainty. In these cases, Whitney observes that the physician often - in his view, rightly - makes a strong suggestion that the patient follows. These situations are areas of decision making where competency evaluations may often arise. It would be especially important for the personal assistant to be present for these decisions to ensure that competency is evaluated in a fashion that is congruent with Buchanan and Brock's competency assessment,<sup>185</sup> or the MacArthur Assessment method.<sup>186</sup>

Providing a personal assistant to adults with M-BMR during health care visits will foster greater communication between the patient, physician, and family or caregiver. It will also help in informing the patient in a way that is meaningful to that particular patient, and will assist in translating that patient's values, preferences, and interests if the patient has a unique way of communicating that the physician is unaccustomed to dealing with. Through greater discussion and understanding between the parties involved, a more collaborative decision may be reached. In cases where the personal assistant is unable to enhance the patient's understanding, and where a surrogate decision maker is necessary, the personal assistant is available to provide continued communication and support to the patient throughout the medical treatment process. Through the advocacy, communication, and support of the personal assistant, and a more collaborative approach to medical decision making that acknowledges the importance and value that the

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<sup>184</sup> See Quill & Brody, *supra* note 177 at 765.

<sup>185</sup> See Buchanan, *supra* note 13 at 23-25. See also Chapter 5 (discussing the Buchanan and Brock competency assessment method).

<sup>186</sup> Grisso & Appelbaum, *supra* note 79 at 165.

patient, physician, and family member or caregiver bring to the discussion, a greater balance of the autonomy of the patient and the patient's well-being will be realized.

### 7.3 ACCEPTING THE CHANGE

It might seem counterintuitive to think that providing a “helper” to a patient with M-BMR would promote her autonomy. However, as was indicated in Chapter 3, autonomous people cannot be extricated from the interrelated social web in which they make decisions. Autonomous decisions are virtually always influenced by external factors. A personal assistant, however, should not be one of these external factors. The personal assistant is there as a conduit of information, a translator. We do not consider individuals of a foreign country less autonomous simply because they require a translator. In the same sense, we should not consider patients with M-BMR less autonomous because they require one. On that same token, the personal assistant's duty of providing support should not detract from the patient's ability to decide in an autonomous manner. A patient whose wife attends a visit and holds his hand is not considered less autonomous simply because he is offered support. Often, patients with M-BMR do not have constant sources of support in their lives. This is an unfortunate result of social stigma they have faced. Providing a personal assistant for such support should be considered a civic duty to a disenfranchised individual.

In the medical sense, it might appear that the personal assistant will be a drain on the time and efficiency of the medical system, but further exploration uncovers many benefits of such an individual. In cases such as Mr. Doe, where he was asked to consider a diagnostic test and sent

home to think about consenting, a personal assistant might have been able to help Mr. Doe understand and feel comfortable enough with the test to assent to it without a follow-up visit.<sup>187</sup>

Additionally, a personal assistant would be familiar with the particular patient and might be able point out particular details that would be important for the physician to be aware of. This could potentially reduce medical mistakes or drug contraindications. At times, family members or guardians fill this role, but sometimes their own cultural beliefs, or personal traits, keep them from raising concerns. A personal assistant, with advocacy as their primary role, would feel obliged to do so.

As with any change to the health care system, the personal assistant might be viewed as a hindrance at first, but over time, as they become more common and accustomed to procedures, they pose great promise for both the effectiveness and efficiency of adult care visits with patients with M-BMR.

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<sup>187</sup> In cases such as these, it is important to note that there is a fine line between support and coercion. *See supra*, Chapter 6, Section 6.2, *Reality: An Ethical Dilemma*.

## CONCLUSION

Respect for a person's autonomy is deeply-rooted in American tradition and in the ideals of informed consent. Due to a history of discrimination and a lack of knowledge about the decision making capacities of adults with M-BMR, in many cases, these individuals have not been afforded the right to autonomously choose their medical treatments. Instead of providing adequate supports, in the form of greater education and added time, the health care system has placed constraints on the physician's ability to empower these adults.

Working within the context of the present health care system, personal assistants provide a means for physicians to more adequately provide information to adults with M-BMR. The personal assistant also provides a more supportive environment for the adult with M-BMR to make the decisions that often significantly impact his or her life and health. With training in ethics, the personal assistant would have the ability to foster a discussion illuminating the various values, preferences, and interests involved, and encourage a collaborative decision. Through the collaborative decision making process, the patient with M-BMR would become more involved in the medical decisions that affect her while also becoming more informed. With greater understanding and more information, as well as an enhanced understanding of the values and interests involved, the patient with M-BMR will be more able to autonomously make medical decisions that promote her own well-being.

In the instances where the personal assistant is unable to enhance the patient with M-BMR's understanding, and an autonomous decision made by the patient is not possible (thus requiring a surrogate decision maker), the personal assistant serves as an advocate for continued communication with the patient and a supportive person that the patient is familiar with. This will ensure that the patient's intrinsic dignity is respected even while her autonomy may be diminished. It will also encourage greater understanding of the procedures that are performed and, thus increase compliance with the procedures. This greater understanding might also reduce the emotional trauma the patient with M-BMR experiences which would promote that individual's well-being.

History and recent empirical data indicate that adults with M-BMR deserve far more respect and support than they have previously received. Providing a personal assistant would further the goals of informed consent and guardianship reforms by providing the medical community with a means of promoting the autonomy of adults with M-BMR in a less restrictive way than guardianship or surrogate decision making. Additionally, it would allow the physician to spend more time attending to the health needs of the patient.

Not every adult with M-BMR will be able to make informed medical decisions with the help of the personal assistant. However, every adult with M-BMR should be granted respect for the extent of autonomy and dignity that they do have and should be afforded the same opportunity to understand the nature of their diagnosis, the potential treatments, and the risks and benefits of those treatments. Providing personal assistants grants them that respect and allows them to realize such a right. Therefore, a personal assistant program should be implemented and a collaborative approach to medical decision making should be considered.

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